

Facing up to disability



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Ways of thinking about and responding to disability have radically changed in recent decades. Traditionally, disability was regarded in terms of sin, karma, or divine punishment. More recently, disability was made a medical issue and defined in terms of shortcomings of body or mind, which had to be prevented or cured at all costs. In the late 20th century, people with disabilities worldwide became more organised and created national and international disabled people's organisations. They successfully demanded that disability be seen as a matter of equal opportunities and human rights, a shift which has now been described in the United Nations Convention on the Rights of Persons with Disabilities. This is a global treaty which has so far been signed by 155 states and passed into law by 127.

Disabled activists and academics make a distinction between **impairment** – in the individual's functioning – and **disability**, understood as the relationship between a person with impairment and their society. By failing to consider the needs and wants of people with impair-



Community-based rehabilitation workers can take eye care into the community, thereby increasing access for people with different impairments. MALAWI

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ments, and failing to make the world more accessible for them, society is in fact responsible for disabling people who have impairments. This is known as the social model of disability.

Disability is shaped by **physical barriers** (e.g. medicine labels which are too small for people with visual impairment to read, or stairs to the hospital entrance which prevent people using wheelchairs from going in) and **social barriers**, including

negative attitudes and cultural messages, and discrimination in employment.

Stereotypes

Stereotypes influence the ways that people without disabilities react to people with disabilities. For example, people with disabilities are sometimes considered to be childlike and innocent, and are spoken down to. People with disabilities are

Continues overleaf ➤

ABOUT THIS ISSUE



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I am delighted to have been asked to be the consulting editor for this special issue on disability and diversity. It covers a range of interesting articles that are relevant for anybody working in community eye health specifically, as well as in the health sector generally. As an amputee myself, I often find myself making jokes to put people at ease around me. Why? Simply because most people are not confident about how to approach or interact with people with disabilities, and humour

breaks down barriers. This journal is jam-packed full of articles that will give you information to boost your confidence. In particular, the section on practical tips for eye care workers on how to engage with people with different impairments, and the poster on guiding someone who is blind, are simple and straightforward.

The editorial, written by Professor Tom Shakespeare, until recently working on disability with the World Health Organization, gives a great overview. 'What does it mean to have an impairment?' is a wonderful interview with Gertrude Fefoame, a blind Ghanaian disability advocate and mother of three. Read about her brilliant insights and powerful solutions to barriers she has faced.

The moving story of disability from a child's perspective is captured by Maria Zuurmond's article. It demonstrates how we need to work in the most inclusive way possible for the next generation.

The articles that follow are full of practical ideas about how to make eye care inclusive and accessible. You'll find some key recommendations, an overview of what inclusion, participation and accessibility actually mean; and a case study from Cambodia.

And the articles on community-based rehabilitation and disabled persons' organisations emphasise the importance of referral to services both inside and outside of the health system.

Read on, and enjoy!

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thought of as dependent and incompetent. Yet, in reality, people with disabilities are like everyone else, with strengths and weaknesses. Throughout recorded history, presidents, military leaders, writers, artists, musicians, sportspeople, and scientists have had impairments, showing that this is no bar to high office or great achievement in life (see www.disabledlives.blogspot.com).

People with disabilities are more likely to be female, older, and/or poorer. When people with disabilities are also of minority ethnic status or gay, their difficulties are even more complex, leading to greater

disadvantage. People with certain impairments are also more excluded than others – for example, people with intellectual impairments and people with mental health conditions are particularly disadvantaged in employment.

How then to improve the quality of life of people with disabilities? *The WHO/World Bank World Report on Disability*, launched in 2011 as an evidence-based summary of the global situation of people with disabilities, provides information on problems and solutions. Rather than reducing disability to simply medical problems and solutions, the social

Glossary: disability

- **Accessibility.** The degree to which information, a service, or a device/product is available to as many people as possible, including people with different impairments.
- **Barriers.** Those things which prevent a person with an impairment from being able to get to, or use, information, services, or devices/products.
- **Disability.** How an impairment affects someone's life; this is determined by the extent to which society is willing to accommodate people with different needs.
- **Inclusion.** The practice of ensuring that people feel they belong and are able to participate in community life, which includes accommodating any person with an impairment.
- **Intellectual disability.** A reduced intellectual ability and difficulty with everyday tasks; the term 'mental disability' is similar but can include mental disorders such as depression or schizophrenia. Other terms used for intellectual disability include 'learning disability' and 'mentally handicapped'.
- **Impairment.** Difficulty in physical, mental or sensory functioning.
- **Mobility impairment.** Difficulty with walking or moving around. People with mobility impairments may be wheelchair users or use crutches, or may need extra time or support from another person to move around.
- **Sensory impairment.** Visual and/or hearing impairments.



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What does it mean to have an impairment?

approach used in the report highlights how social arrangements, policies, and practices can either *disable* or *enable* people with impairments. For example, failure to provide rehabilitation and assistive devices means that people remain dependent and cannot improve their functioning. If children with disabilities are not able to attend school, they may be denied the chance of future employment. Inaccessible transport means that people with mobility impairments cannot access health care, education, or employment.

The way forward is clear. As mandated by the United Nations Convention on the Rights of Persons with Disabilities, governments should promote access to health, education, livelihood and other opportunities. People with disabilities should live in the community, rather than institutions. In general, the best strategy is removing barriers by making physical changes and by working to improve the attitudes and skills of staff. This will ensure that health care and other services are available and accessible to all. Sometimes, it is necessary to provide additional services specifically for people with disabilities, to ensure they can benefit from the specific services they require, for example rehabilitation or support.

Eye care practitioners should examine their own practices to ensure that they treat people with disabilities in the same way as they treat other people. After all, people with disabilities have the same needs, are vulnerable to all the same risks, and require the same access to mainstream services as other people. In busy clinics, eye care practitioners may think only about the person's eye health and forget about the person's general health and their other needs, for example education, rehabilitation, or support with getting a job.

People with disabilities are entitled to respect and dignity, and should be treated fairly. Service providers – such as eye clinics – must be flexible and willing to adapt environments and practices to accommodate different ways of working, communicating, or moving around.

Prevention of disabling health conditions of course remains a priority for global development and public health. But for the millions of people worldwide who live with impairment, their best hope of flourishing lies in a society which is committed to the principle of inclusion and willing to remove any barriers in their way.

Further reading

- 1 United Nations (2006) *Convention on the Rights of Persons with Disabilities*, UN, New York.
- 2 WHO (2011) *World Report on Disability*, WHO, Geneva.
- 3 WHO (2010) *CBR Guidelines*, WHO, Geneva.



Sightsavers

Gertrude Oforiwa Fefoame is the Africa Social Inclusion Advisor for Sightsavers, an international charity which works in low- and middle-income countries to restore sight and support people who are irreversibly blind. She spends her time advocating and providing technical support for the inclusion of people with disabilities in eye care and other development projects.

'When I was ten years old and in school, I realised I couldn't read from the blackboard like the other children in my class. My family took action immediately, and I was seen by an ophthalmologist at the most advanced eye clinic in Ghana at the time. I was referred to an optometrist and given spectacles, but I needed a new prescription every three months. Eventually we were told that there were no other reading glasses that could help.

'Even though I grew up in the vicinity of the first school for the blind in Ghana, I remained in my mainstream school and continued to a mainstream secondary school at the age of 13. By the time I was 14, it was really difficult for me to read textbooks: I could only read large print and my own handwriting. I learned mainly by listening and also working with my classmates, who gave me support as we studied and did our homework. Some teachers would offer extra help after the class, and others were willing to read what they were writing on the board so I could hear and follow. But it was not a formal low vision service. I didn't know that any existed as low vision students at the School for the Blind then were all learning like blind students.

'Later, when I had finished school, I met one of my teachers, and he explained

that the headmaster of the school had received some exposure to special needs education and gave the teachers hints on how they could support me. Because I was not involved in the discussion and did not know about my rights then, I didn't know I had the right to demand such services. I didn't know that what those staff members did for me was not charity, but their responsibility. This meant I didn't feel I was able to ask for the additional support that I really needed in school.

'At the hospital, when they could no longer improve my vision or even prevent it from getting worse, nobody explained to me what the condition was and what I should expect in the future. I am not sure whether my relatives had a better understanding than I had, but they didn't tell me much. It was also not normal for a child in my culture to ask too many questions.

'When it came to my final examinations, although the school applied for

'I learned mainly by listening and working with my classmates'

questions in large print, two weeks before the examination information reached me that the examining board could not provide this. Fortunately, my biology teacher had an idea – I could use a hand magnifying lens, like the ones we

used to examine specimens! Although I could see only a few letters at a time, as it was such as small lens, I was able to read the exam questions. I still have the lens today although it is no longer of use!

'Soon after I left school, there was an advert in the paper about teachers who could be trained to support people with visual impairment. My uncle saw this and investigated – he found out that I could go to the school for the blind where I could learn to read and write Braille, so I could

Continues overleaf ►

continue my education.

'The admission form for the school for the blind had to be signed by an ophthalmologist, to certify that I needed such a service. My ophthalmologist, who I've been with for many years, said he thought it was a good idea for me to go, but he couldn't say why he had never suggested this before!

'When I went to the school for the blind, which was near where I grew up, the people I knew in the area reacted very differently to me – even though my vision hadn't changed. They were sad, would say how sorry they were for me, and spoke with such pity!

'I was visited at the school by a lady who is blind and who was already enrolled at the teacher training college. I listened to her talk about her experiences and then I knew that I had a future.

'Over the next two decades, I qualified as a teacher, then specialised in special needs education, followed by a degree course in education. I taught psychology, counselling, and special needs education at the teacher training college.

'Maturing as a person with a visual impairment was very difficult – society didn't make it easy. Thinking back, I knew that the way people reacted to me when I went to the school for the blind was wrong but I didn't know what to do about it. I struggled with this and similar concerns for many years.

'Then, in the early 1990s, things changed when I attended a workshop initiated by the World Blind Union's Institutional Development Programme (IDP). IDP is an international capacity building programme for organisations of and for the blind mainly in Africa, and is sponsored by Sightsavers and Perkins International. At the workshop, I realised that continued advocacy and awareness raising would be required to address the challenges faced by individuals and organisations for the blind. What stood out for me was that everybody had a role; you could initiate change from wherever you were and engage others to join you. It had a great impact on me and encouraged me. So I strengthened my participation in the organisations of persons with disabilities at national, regional (Africa) and global levels, and served in different leadership positions.

'Whenever one is able to push disability behind and move on with life, those with positive thoughts see the person and not the disability. Sometimes, my friends forget that I cannot see – it is because they see me, and not my visual impairment. Everybody in society can be like this – particularly if we start by educating our children that people with disabilities are just the same as everyone else.'

If I could choose ...

Eye care practitioners would be careful how they promoted the restoration of sight

'Don't create the impression that, if vision cannot be restored, that it is the end of that individual. Right from the beginning, eye care practitioners should say: "I know you are managing, but some of the challenges you are facing can be limited." Then, if the operation is not successful, they can say: "Well, you remember the conversation we had, about how well you were managing, this is what we need to continue and strengthen. There are also these services I can refer you to for more support ..."'

Eye care practitioners would talk to people with disabilities, instead of their guides or carers

'People think the person who walks in with you knows more about you than you yourself, even if you are an adult. It is usually because there is no eye coordination, and sighted people feel more comfortable talking to people with whom they can link eyes (make eye contact). This should be explained to people not just in the eye profession, but across the board. So, more awareness within the health training, and refresher courses around disability, are needed.'

Pharmacists would ensure people with disabilities understood how to use their medicines

'The ideal would be the provision of a Braille label to those who can read it. For those who can't, pharmacists can help them to examine the package, and perhaps the content, so they are able to identify the correct dosage. This could also be provided by the Support Services Department, which (ideally) every hospital should have.'

People promoting eye health would ensure that people with disabilities also get the information they need

'If you are giving a health talk, or doing health education in a community, check that people with different impairments are also there to listen. There will certainly be several people with impairments in the community – you are responsible for ensuring that they also hear your message. Don't rely on others to tell them. Remember, also, that people with a visual impairment cannot read posters.'

People working in eye clinics would value all patients

'People coming for eye care often have some visual disability already. They will experience fear, anxiety, and confusion, as well as worries about the costs. So when they come to the clinic, and the receptionist – whoever is doing the papers – is harsh, then it gets much more difficult. If the people you meet are warm and friendly, it is much easier. The way people working in eye clinics treat people with impairments is very important: be polite, understanding, and encouraging. Despite the fact that there is so much work that needs to be done, the eye team have to be very professional – this should be part of their training.'

People with disabilities would be included in the health sector

'Eye health programmes need to include people with disabilities in all aspects of health promotion, blindness prevention, and eye care delivery. For example, people with disabilities would make excellent counsellors for people who have become disabled, as they are good role models and mentors.'

Counselling would empower people with impairments

'This is the type of counselling that deals with the inner awareness and self-actualisation of the person – it is about that person reaching their full potential, disabled or not. Yes, it's good to tell people that there are services available for them, but this is about their head or heart, which is telling them that the world has come to an end. That is the perspective good counselling tries to change. Counsellors must say to people: "This is not your end", and talk to them about others who are doing well and even excelling in life, despite their impairments.'

'Counsellors must also empower people as individuals: tell them they have a right to ask for the assistance they need, that they have a right to participate. Help them to develop assertiveness and confidence in themselves as an individual – a platform which every person needs to develop and grow. This is when people with impairments can grow from strength to strength.'



Understanding the wider needs of children with disabilities



Maria Zuurmond

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It is easy for all of us to focus in on our own area of expertise, and treat just one aspect of a child's health. For the typical community eye worker this focus is, of course, on providing eye care. In reality, most children and their families will have much broader needs and priorities. Without addressing these other issues, or at least referring families to other services, your work may have less impact.

In this article we share some experiences from a parent training project in Bangladesh, funded by CBM and carried out in partnership with the Child Sight Foundation, which aims to better equip parents to provide care for children with cerebral palsy. Many children with this condition will have a range of other health issues, which can include being visually impaired.

A key first step in our project was to undertake initial interviews with families in

order to better understand their priorities.

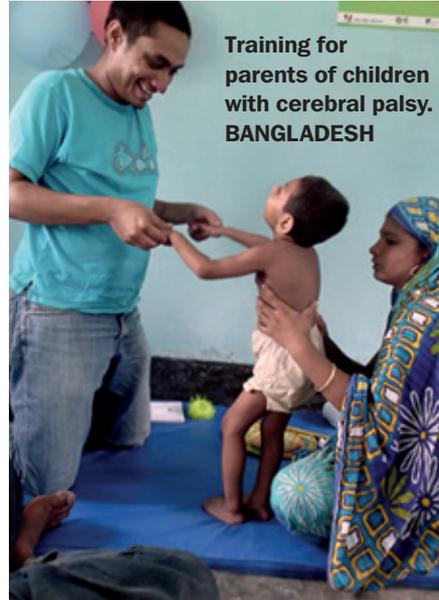
We also wanted to understand, by talking to the children, what their daily lives were like and what was important to them. Being able to go to school was a priority for some children, was the impor-

tance of not only focussing our support on access to health services, but also on improved access to education.

What can eye care workers do?

As an eye care worker you cannot do everything. But the examples below illustrate that it is really important to take some time to find out what other services exist in your local community, and how best you can refer families to these services. In Sonia's case, we found out what nutrition programmes there were in the district and made contact with them.

It is a good idea to think outside the health or eye care 'box'. It might be that you can link a family to a non-governmental organisation working on livelihoods and income-generating activities. Or you might find time to promote your services to a local school and talk to the teachers about how they can be more inclusive of children with visual impairments. By reaching out and connecting children with services, you can make a difference in the quality of their lives.



Maria Zuurmond

Case studies

Sonia's story

Sonia* lived with her parents and two younger siblings in a rural district in Bangladesh. She had multiple disabilities, was unable to stand unaided, and had both visual and hearing impairments. When we met her mother for the interview, it was obvious that Sonia was malnourished, and that she had a skin condition and other health problems. She spent most of her time sitting on a red plastic chair outside of the house; she didn't play with anything because her mother explained that she was unable to hold anything in her hand.

Sonia was diagnosed with cerebral palsy during an earlier medical camp, and was referred and treated for two cataract operations, which were both provided free of charge. She was also given glasses, but never wore them, and was beginning to develop posterior capsule opacification.

Her mother explained that one of the family's main challenges was the fact that Sonia was often ill, for example with pneumonia, and they had already sold three cows to pay for her treatment. Feeding and toileting were identified as their main concerns in caring for Sonia: "The hardest thing is the feeding, and

more than that is the toileting ... Before she was able to eat more food than now. She used to take some bread and milk, but now the only thing she takes is some rice and milk. The rice has to be mashed up. She will only take 3-4 tablespoons and then refuses it. This has been for the last 3-4 months."

This interview raised important issues for us in planning our own parent training project. We were completely focused on providing a training course, but clearly there were a range of broader health issues that also needed to be addressed. We couldn't conduct the training in isolation. We needed to explore links which could be forged with local nutrition programmes, and also how to improve access to address primary health care needs.

Very sadly, since conducting this interview, Sonia has died.

Atia's story

Atia* is 14 years old and lives with her two younger sisters and her parents. She has cerebral palsy, cannot walk, and is completely dependent upon members of her family for all her personal care. She

loves to attend school, although she cannot always get to school because it is not an easy journey. Perhaps this is one of the reasons why she has been studying in the same class (Grade 1) for the last three years, and the rest of the

'I like it when my friends come to me at the school'

children in the class are younger than her. Her mother takes her to school in a wheelchair, but when crossing from the main road to the side road her mother has to carry her, and her younger sister has to carry the wheelchair. This is not an easy task, especially as Atia gets older.

Atia explains to us what make her feel both happy and sad: "If my mother does not take me to the school I feel sad. My mother is busy, which is why sometimes she can't take me to school. Taking me to the school is very pain-tasking job for my mother; I feel bad seeing her pain."

"I like it when my friends come to me at the school. They help me with crossing the stairs and they don't get angry. Teachers are good at school. They teach us, they don't get angry. They love me. They call me by my name and ask me how I am doing - that's why I feel good."

* All names in this article have been changed.



Improving communication with patients with a hearing impairment



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The main barrier to communication for people who are hearing impaired is the lack of consideration by others. These patients can face prolonged or unnecessary illnesses due to inadequate communication with their health care providers.

However, by being prepared, and by preparing the patient, health workers can ensure good communication, thereby giving patients access to appropriate and effective health care.

Please note that patients with both visual and hearing impairments require even more consideration!

Before the appointment

Patients with hearing impairments, with or without hearing aids, may communicate in a variety of ways with health personnel. Some patients speak and speech-read or lip-read, some use sign language or communicate by writing notes, and some bring someone with them to interpret. When advertising the eye clinic, or booking appointments, include information for patients on what to bring with them – such as their interpreter or their hearing aid.

Reception and waiting areas

Waiting areas in clinics can be very noisy. Patients with severe or profound hearing loss will not hear shouted instructions or staff calling out their name. Those with moderate hearing loss can also have difficulty. The following general provisions may be helpful:

- In the waiting room, in addition to calling out the patient's name when it is his/her turn to be seen, use a number system or a sign (e.g. a board with the patient's name written on it).
- Write the most important information on clearly displayed signs.
- Put up a sign in your waiting room asking patients to inform you if they have a hearing impairment, and whether a sign language interpreter is available. Do not rely on being able to see a hearing aid – not all patients with hearing impairments wear these.
- If a patient with a hearing impairment calls in advance to make an appointment (or if someone else calls



Seema Rupani Shah

Examination of a deaf child in the presence of an interpreter. The doctor (right) is facing his young patient and has a pen and paper at hand. KENYA

- on his/her behalf), ask how the patient prefers to communicate and whether a sign language interpreter is needed.
- If you know a patient is hearing impaired, make sure the consultation takes place in a suitable setting (see next section).
- Keep a note on the patient's file with details of any communication requirements.

During an appointment

1 The consultation room

- Give the patient privacy: they should be able to ask you to raise your voice without fear that others will hear about their medical history.
- Minimise distractions. This is even more important if your patient is a child.
- Reduce background noise.

- Ensure the room is well lit, so that the patient can see your face or any written information they may be given.
- Ask the patient to wear their hearing aids (if they have them and find them helpful) and sit closer to them than you would to another patient.
- If possible, have a helper of the same gender as the patient in the room.
- When adult patients are accompanied, always ask them before you start if they would prefer to be alone with health personnel in the consultation room. Do not wait until the questions become uncomfortable for the patient.

2 Remember that your face is an essential communication tool

- Face the patient, not their interpreter or carer.

PARTICIPATION



Diane Mulligan
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'Nothing about us without us' has been a slogan of the disability rights movement for decades. Participation is fundamentally about people with disabilities participating in decisions that relate to them so that actions affecting people with disabilities are not planned or performed without their input. This guiding principle highlights the need for people with disabilities to be brought into the process in such a way that they can directly influence decisions. This results in greater inclusion of people with disabilities and also brings with it lasting change.

Extensive involvement of people with disabilities will build skills and capacity. At the same time, people with and without disabilities working alongside each other can often foster changes in attitudes and understanding about the abilities, contributions, and aspirations of people with disabilities.

People with disabilities are often empowered and enabled by the confidence and skills that result from the fostering of genuine partnerships. These partnerships can include partnering with families, wider support networks, service providers, and community leaders, where appropriate. Working in partnership with disabled people's organisations (DPOs) is a very effective strategy (page 12).

Supporting people with visual impairment

Communication

Here are some techniques to keep in mind when meeting with a patient with visual impairment.

- Remove any masks or face shields.
- Do not have anything between your lips (cigarette, pen, etc.) or in your mouth (chewing gum, sweets, etc.) as this can distort lip movement when you are speaking. Avoid placing your hand or an object in front of your mouth when talking.
- Have the light on your face rather than on the person you are talking to. This makes it easier for them to read facial expressions and to lip-read.
- Support your speech with facial expression where you can, e.g. look happy if you are giving good news and sad if you are giving bad news.
- When signing, hold your hands up at chest level to enable both your face and hands to be clearly seen.
- Understand and use the local culture of gestures, expressions and accepted physical contact (or absence of it).

3 Ensure that you speak effectively

- Speak normally, not too fast or too slowly. Certain sounds can be distorted or lost if speech is rushed or slowed down too much.
- Use short, simple sentences.
- Do not exaggerate your speech or lip movements.
- Ask questions if you are not sure you understand what the patient is saying.
- Patients tend to agree with their health care workers, sometimes without understanding what has been said to them. After every important point or message, ask the patient if he/she has understood you and, if necessary, ask him/her to repeat the message or instructions back to you (especially important if the patient is unaccompanied).

4 Use other means of communication, e.g. writing and signing

- If the patient can sign, use an interpreter. If at all possible, learn the local sign language yourself. This can be fun and can be done with other colleagues.
- Be prepared to write down any questions or answers, and give the person with a hearing impairment the opportunity to do the same if necessary.
- Write down important information, e.g. instructions for taking medicines, to give to the patient. Have this information available in alternative formats (e.g. large print) for people with impaired vision or give the information to the person assisting them.
- Use pictures and drawings to help the patient to understand you.

- Introduce yourself and say your name
- Use the name of the person so they know you are talking to them.
- Face the person and talk to them, not the person accompanying them.
- Be specific in giving directions: say 'left' or 'right' rather than pointing.
- Identify the room you are in if the person cannot see well enough to recognise their surroundings.
- Identify and name any other people in the room or involved in the consultation.
- Read out written information, including rights to treatment and associated risks.
- If the person moves to a new location, tell them who is in the room and offer to describe the environment.
- Do not leave the person alone in the centre of a room. Make sure they can touch a table, chair, or wall to maintain orientation to their surroundings.

Children's education

There are different models for educating children with visual and other impairments, which include educating children in

'special schools' (schools for children with specific impairments), and educating children in a mainstream school (known as 'inclusive education'). The comments below apply equally well to any model, and eye care workers may wish to spend time talking to parents about them.

- All children have a right to education.
- Education will give a child more opportunities in the future.
- It is important that children with disabilities spend time with their peers to make friends, gain independence, and develop a sense of belonging in the community.
- Children with low vision will need regular and ongoing assessment to check their refraction and whether they are using the most appropriate low vision interventions. The interventions may need to change as the child grows older, and as his or her educational demands increase. For example, the font size in school books will get smaller as the child progresses through primary school.

With thanks to Clare Gilbert, Co-director, International Centre for Eye Health, and the authors of Disability Inclusive Practices in Eye Health. CBM 2011. www.cbm.org/disability-inclusive-eye-health



FROM THE FIELD

Mobility impairments and access

Nagarathna, CBM Country Director: Sri Lanka, describes how she encouraged Joseph Eye Hospital in Sri Lanka

to be more accessible. Nagarathna has a mobility impairment, and uses crutches to move around.

Nobody with a disability had ever come to Joseph Eye Hospital to work with them on increasing accessibility – it was all very new to them! I had to make several visits to the various hospital departments before they were able to understand the difficulties faced by people with mobility impairments.

Although the main entrance, wards, pharmacy, and optician's shop were accessible, the finance, administrative and management departments were not. But this is important: people with mobility impairments may want to discuss their fees, or need to talk about problems they are having.

When we started to talk about how the hospital could become more accessible without making big infrastructure

changes, the idea no longer seemed so daunting and the hospital team were keen to make the necessary changes.

Some low-cost ways to improve access for people with impaired mobility include:

- Building a proper ramp with a railing – not too steep.
- Having at least one toilet that is accessible to someone in a wheelchair: a wide door, a western commode, a hand rail, and a low basin.
- Using non-slip flooring that is safe for people using crutches or calipers.
- Creating a section of the reception desk that is low enough so someone in a wheelchair can see the receptionist (and be seen by them).

Finally, I think it is important that eye clinics and non-governmental organisations employ people with disabilities in different capacities – this sets a good example and helps to ensure that the needs of disabled people will be met.



CASE STUDY: CAMBODIA

Addressing disability in the health system at CARITAS Takeo Eye Hospital



Manfred Mörchen

Consultant ophthalmologist and CBM medical advisor to CARITAS Takeo Eye Hospital, Cambodia.



Gail Ormsby

PhD Candidate, Centre for Eye Research Australia, University of Melbourne.



Te Serey Bonn

Programme Director, CARITAS Takeo Eye Hospital, Cambodia.



David Lewis,

Strategic Programmes Director, CBM Australia.

In recent years, CARITAS Takeo Eye Hospital (CTEH) in Cambodia has worked hard to be more inclusive of people with disabilities. While there have been some challenges along the way, the overall results of the new practices appear to be very positive.

The first change came in 2008, when the old, run-down eye hospital was replaced with a brand new facility. The major donor, CBM, encouraged the local partner CARITAS Cambodia to grasp the opportunity to design the new building so that it would meet high standards of accessibility. CBM emphasised that a 'universal design' approach, reducing the (physical) barriers for everybody, regardless of age and ability, could lead to a win-win situation for all patients, not only those with disabilities. Guidance from CBM (based on the document *Promoting universal access to the built environment*¹) was invaluable for local architects, and the result was the construction of an eye hospital with significantly improved physical accessibility.

The second important change in strengthening practices related to people with disabilities, beyond just physical accessibility, was triggered by the Avoidable Blindness Initiative funded by the Australian Agency for International Development (AusAID). This programme emphasised wider issues including disability inclusion, gender, and child protection. Eye care projects had to report specifically against these issues, for example, physical accessibility for people



CARITAS Takeo Eye Hospital

Better physical accessibility and greater awareness of disability by hospital staff have improved the inclusion of people with impairments. CAMBODIA

with disabilities and the number of eye health services with documented referral pathways to disability services and disabled people's organisations.² In collaboration with CBM Australia, a number of activities on different levels were implemented between 2009 and 2012:

- A 'knowledge, attitude and practices' (KAP) survey was conducted on people with and without self-reported impairment. This provided a 'baseline' or starting point from which to measure the hoped-for improvement.
- Training of local staff on inclusion – facilitated by a partnership between CBM Australia and the Nossal Institute

for Global Health, University of Melbourne.

- In order to build and share knowledge, and to foster collaboration and partnership, workshops on disability inclusive practices were also conducted with local hospital staff, local provincial health authorities, community-based rehabilitation (CBR) organisations, partner eye care organisations, government officials and the National Program for Eye Health.
- A manual, called *Disability-inclusive practices in eye health*³, was written in collaboration with the CBM Australia-Nossal partnership and distributed to those involved in the work. A condensed, translated version was also distributed to all local health authorities in Takeo province.
- CTEH advocated for consideration of disability inclusive eye care practices into national eye health guidelines. As a result, Cambodia's National Programme for Eye Health – run by the ministry of health – made disability inclusion part of the national primary eye care curriculum from 2011.
- A key recommendation for improved disability inclusive practice in eye health relates to access to low vision services. CTEH has developed a low vision department, employing refractionist nurses trained to provide low vision services.
- Collaborations with both mainstream schools and specialist schools for blind

BARRIERS FACED BY PEOPLE WITH DISABILITIES



Diane Mulligan

Deputy Director, Advocacy and Alliances for Inclusive Development, CBM.

The specific identification and removal of barriers is the essence of accessibility. Barriers can be grouped into four categories:

- 1 Physical or environmental barriers.** Access to buildings, schools, clinics, water pumps, transport, roads, paths, etc.
- 2 Communication barriers.** Written and spoken information including media, flyers, internet, community meetings, etc.

- 3 Policy barriers.** Including legislation that discriminates against people with disabilities, and/or an absence of legislation that might otherwise provide an enabling framework. Departmental and organisational policies can also be addressed here.
- 4 Attitudinal barriers.** Including negative stereotyping of people with disabilities, social stigma and other forms of overt discrimination. It is not uncommon that disability is associated with cultural beliefs about sin, evil and witchcraft. People with disabilities often report that attitudes are the most disabling barriers of all.

children, relating to low vision and disability inclusion generally, have been strengthened.

- Improved collaboration with the local CBR organisation, Cambodian Development Mission for Disability. This has strengthened referral and support for people with disabilities and for other poor patients. This includes waiving user fees, transportation assistance, and distribution of food vouchers.
- The development of a computerised health information system with data collection on self-reported disabilities.

The results from the KAP survey⁴ have been very useful, especially in highlighting the barriers which prevent all members of the population from accessing eye care. For example:

- Only 19% of people with self-reported impairments (including those related to vision) reported being able to travel to the eye hospital on their own, whereas nearly twice as many people with no reported impairment (36%) claimed to be able to travel alone.

- Only 83% of people with self-reported impairments said that they would look for treatment in case of an eye problem, compared with 95% of people with no impairment.

The implementation of the new low vision department at CTEH has been especially successful. The refractionist nurses who were trained in low vision care received ongoing monitoring. They have been able to integrate the new service into outpatient department activities. In addition, rehabilitation of visually impaired patients in the hospital and through growing collaboration with mainstream and specialist schools is leading to improved outcomes for these patients.

The inclusion of a disability component in the new health information system raised several problems. These included the need for a simple definition of disability in this context (e.g. a definition of 'hearing impairment' in an environment where hearing tests are not available) and staff members' concerns about the additional workload required. Asking

patients to self-report any disabilities – for example by including the Washington Group's self-reporting questions⁵ in patient registration forms – is highly recommended, as it is both simple and efficient. CTEH is now able to provide evidence that a significant number of patients have other impairments in addition to visual impairment.

Overall, our efforts to strengthen disability-inclusive practices appear very worthwhile, but more research is certainly needed.

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Disability: recommendations for eye programmes

In 2012, CBM's Medical Eye Care Advisory Working Group met in Hyderabad, India to discuss the inclusion of people with disabilities in eye care.

As a result of these discussions, the following recommendations were made:

- Involve local disabled people's organisations (DPOs) in planning (page 12).
- Appoint a member of staff as the coordinator for disability inclusion in all eye units (this may be a part time role).
- Identify barriers to access, both internal and external, noting which are easy and which are difficult to fix. Put in place an action plan to address these.
- Consider any additional needs based on gender and age.
- Ensure that eye care services are comprehensive and include health promotion, disease prevention, curative medical and surgical services, and rehabilitation services.
- Ensure counselling, links and referrals to rehabilitation and education services are available to people who cannot be helped clinically. Ensure these services also refer patients to eye units.
- Staff with the heaviest loads – such as ophthalmologists – need to know that they can (in a caring manner) refer patients to other skilled staff in the unit.
- Employ people with disabilities to work in eye clinics.

- Ensure physical accessibility as well as large, colour-contrasting signage.
- Specifically plan for the provision of services for hearing impaired people.
- Include disability-inclusive practices in training curricula.
- Provide disability-inclusive training for eye unit staff and raise awareness with other stakeholders. For example, simply training staff to say: 'I can refer

you to XYZ, because there isn't anything more I can do for you' versus saying: 'Nothing can be done for you', can make an enormous difference to 'quality of life' or 'whole of life' outcomes and the mental health of patients with long-term visual impairment.

Colin Cook, Babar Qureshi, Harpreet Kapoor, Dominic Misquith, and David Lewis

Improving access for women and girls with disabilities

Nearly all eye health programmes strive to reach the most marginalised people. They also seek to be gender sensitive, ensuring equal access for all people. Women and girls with disabilities (including those with impaired vision) are some of the most marginalised people, as they face the triple discrimination of being female, having an impairment, and being among the poorest.

It is important that eye health programmes consider how they can support women with a disability. Here are some practical tips:

- Consult with women with disabilities to identify what is blocking their access to eye care, and to talk about how best to overcome these barriers
- Raise awareness among staff and collaborators about the impact of disability on women and girls and work together to address barriers

- Appoint a coordinator for disability inclusion, who understands gender sensitive practice (part-time or full-time)
- Collect and analyse data by gender, age, and disability, for example by using the Washington Group self-reporting questions.
- Employ women with a disability in your programme.
- Develop networks and two-way referral between your programme and primary health care, rehabilitation, education, and DPOs.
- Ensure that women and girls with disabilities who cannot be assisted through medical intervention are referred to other services, such as education, rehabilitation, livelihood, social inclusion and health services.

With thanks to Joanne Webber, Chelsea Huggett, and CBM partners in India and Cambodia.

Assisting people who are visually impaired

Can I help you?



Guiding

Walk side by side. Allow the person with impaired vision to set the pace and to hold your elbow (hand to elbow).



Meeting and greeting

Always treat a person with impaired vision as you would anyone else. Introduce yourself first before offering help.



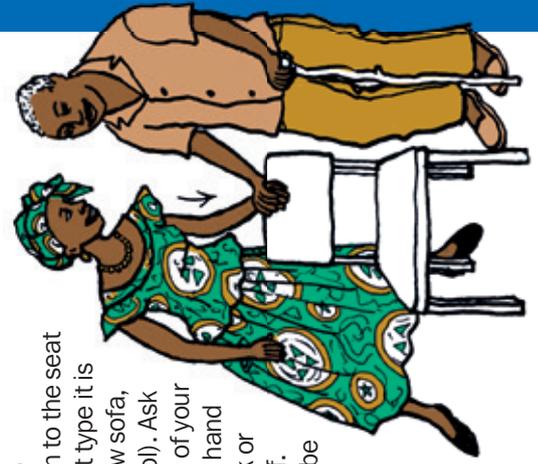
Steps, stairs and slopes

Tell the blind or visually impaired person whether you are going up or down, and allow time for him/her to hold the handrail. Go one step ahead and take a slightly longer stride on the last step to allow your partner space.



Doorways

Tell the person whether the door opens towards or away from you. Go through the door with your partner on the side of the hinge. Open the door with your guiding hand. Allow your partner to feel the handle, follow you through the door, and close the door behind both of you.

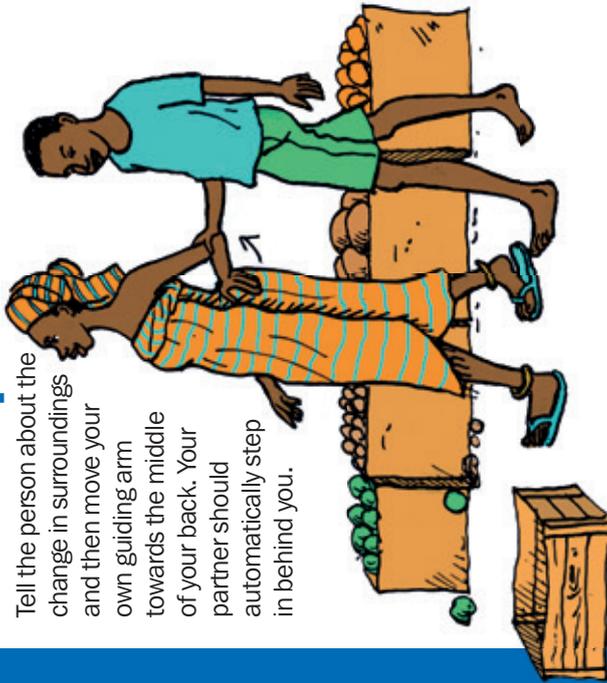


Seating

Guide the person to the seat and explain what type it is (upright chair, low sofa, armchair, or stool). Ask him/her to let go of your arm and place a hand on the seat back or on the seat itself. He/she will now be able to judge its height and sit down safely.

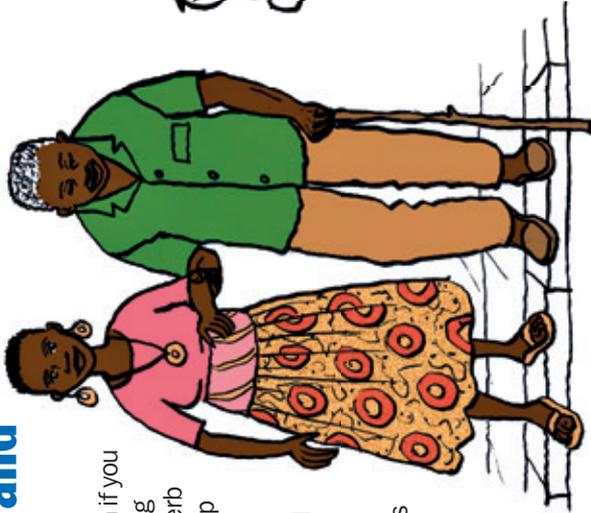
Narrow spaces

Tell the person about the change in surroundings and then move your own guiding arm towards the middle of your back. Your partner should automatically step in behind you.

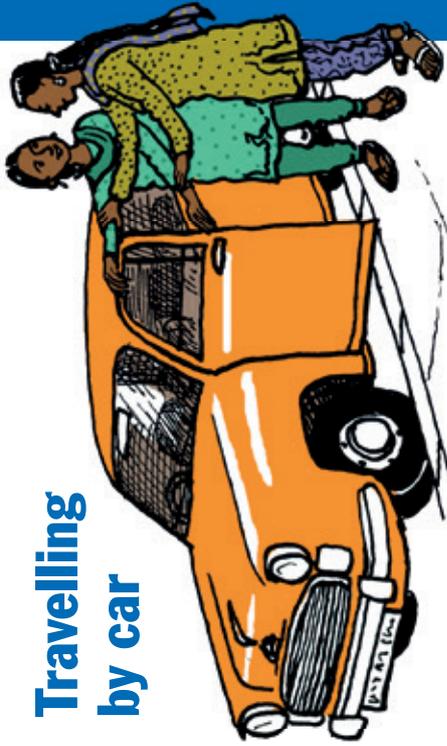


Roads and kerbs

Tell the person if you are approaching 'kerb up' or 'kerb down' (the step onto or off a pavement or sidewalk), and pause slightly before taking the step. Cross the road using the shortest distance and go straight across.



Travelling by car



Tell the person if he/she is getting into the back or the front seat of the car, and whether it is facing left or right. Place your guiding hand on the door handle and allow him/her to slide his/her grip hand down your arm to the door handle. With the other hand he/she will be able to note the car roof and lower his/her head appropriately. At the end of the journey, get out first and help your partner out.

Remember!

Incorrect position



'Don't pull me'



Correct position



'Walk with me'





A vision for inclusion



Victor John Cordeiro

Advocacy Coordinator: World Blind Union, Bangalore, India.

Nandini comes from a remote village in Karnataka, in the south of India, and was blind at birth as a result of retinitis pigmentosa. She has faced many challenges – including attempts to exclude her from school – because of her visual disability. In high school, Nandini made contact with the National Association for the Blind (NAB India) and local self-advocacy groups of people who are blind or visually impaired.

Once she left school, Nandini was asked to become regional coordinator for the All India Confederation of the Blind (AICB). AICB is a coordinating body made up of

22 grass-roots and state-level associations or organisations working with people who are blind, and is also a member of the World Blind Union. Nandini's remit was to promote the empowerment of women and girls who are blind or have impaired

vision who, like her, faced discrimination, injustice, abuse, and violence.

Nandini was later promoted to national coordinator of AICB, and her efforts resulted in policy changes to make voting in elections accessible for people with impaired vision, as well as improvements in their ability to access education and earn a living. She presented papers on related issues to international forums organised by the World Blind Union.

Nandini now works with ActionAid, where she is in charge of promoting the rights of women, including those with disabilities. She writes, composes, and sings revolutionary songs to encourage women in their struggle for equity and justice.

Nandini's contact with local self-advocacy

groups, NAB India, AICB and other such disabled people's organisations, have significantly contributed in shaping her attitudes, perspectives and building capacity to deal with the challenges which blind or partially sighted women and girls

'Nandini faced many challenges, including attempts to exclude her from her school because of her visual disability'



World Blind Union

Nandini uses music to deliver her message of empowerment. INDIA

face in day-to-day life.

Nandini says her association with these organisations has boosted her morale, provided her with exposure to a wide range of issues, and prepared her as an activist in order to initiate systematic and organised struggle. This has enabled her to address injustice and exclusion in an organised and systematic manner.

Disabled people's organisations: a valuable link for eye care workers

Most countries have disabled people's organisations (DPOs). These organisations are founded and run by people with disabilities, for people with disabilities.

Local DPOs tend to be linked to organisations at provincial/district level, which are in turn linked to DPOs at national and eventually international level. These organisations exist for disabilities in general or for specific impairments, such as visual impairment and blindness. The World Blind Union is one example of an international DPO for people with vision impairment.

DPOs can act as a valuable link for eye care workers. A DPO can connect people with vision loss to other DPO members, as well as to community organisations that support people with disabilities. It is therefore good practice for eye care workers to make contact with local DPOs.

There are several ways in which DPOs can help, e.g. raising awareness, advocacy, disability management and improving disability inclusion within organisations.

DPOs can help the eye clinic by:

- Giving practical advice on how to make a clinic more accessible and user-friendly, whether for people with visual, hearing, intellectual or mobility impairments
- Providing training on disability awareness to encourage positive perceptions and dispel myths about disability among clinic staff
- Encouraging referral of people with impaired vision for ongoing eye screening, and of people with other impairments for regular checkups
- Encouraging referral of people with impaired vision to the DPO, and for other rehabilitation or education opportunities
- Actively seeking people with disabilities to attend screening
- Disseminating promotional messages about eye health to ensure that all DPO members have access and can further promote this information to other community members with disabilities.

DPOs can help patients by:

- Advocating for them, and training them in self-advocacy skills

- Mentoring people with a permanent impairment in the development of independent living skills
- Creating connections to community-based disability and other services
- Creating connections to other people with disabilities.

Guidelines for referral

- Develop clear two-way referral pathways and effective referral systems, including the appointment of a key staff member to oversee referrals and to maintain an up-to-date list of disability services and DPOs.
- Improve awareness of the presence and roles of disability services and DPOs among all staff.
- Connect with local CBR services, other disability services, inclusive education options and DPOs to improve knowledge of their role and formalise referral processes.
- For women with disabilities, determine whether there is a preference to meet with a female disability service or DPO member, and ensure this is clearly indicated on the referral.

Compiled by David Lewis and Joanne Webber



Reaching out to patients with intellectual disabilities

Worldwide, 1.04% of the population is estimated to have an intellectual disability; however, this proportion has been found to be higher in low- and middle-income countries.¹

According to the WHO, 'intellectual disability' is defined as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills'. This results in a reduced ability to cope independently, which begins before adulthood and has a lasting effect on development.

In many poor or remote communities, people with intellectual disabilities are stigmatised and their families may become isolated. Outreach and community services have an important role to play in ensuring that people with intellectual disabilities get access to the eye care they need.

People with intellectual impairments may have a higher than average prevalence of visual impairment. Sight problems may also result from brain damage, cerebral visual impairment, or may be associated with other causes of intellectual impairment.² Individuals with intellectual impairments may have to be reminded about how to take care of their spectacles and about the importance of eye tests, and they may need support in order to attend for tests.

People with intellectual impairments may struggle to get the same quality of care when they do come forward for medical treatment. In the UK, the health outcomes of people with intellectual disabilities are poor, and some have died unnecessarily in hospital because of failures to understand and address their particular needs.³

What must eye care workers know?

- People with learning difficulties may find it difficult to understand complex instructions or questions. They may struggle to understand the consequences their decisions may have on their health.
- They may find it difficult to make decisions and will take longer to do so.
- Some people with learning disabilities may struggle with reading and writing and may have additional challenges such as physical and/or sensory impairments.

- Health problems might be accompanied by unusual signs and symptoms – for example, someone with severe learning disabilities might demonstrate discomfort by self-harming.
- People with learning disabilities often rely on family members and carers to provide emotional support and to help them feel safe.
- There might be barriers to attending health services, such as poor physical access, transport costs, difficulties in finding their way around, or having no-one to accompany the person.

Improving our service

Simple, cost-effective changes can make a big difference in our ability to provide quality care to people with intellectual disabilities. Here are some examples.

General

- Allow more time for people with intellectual impairments. For example, book double appointments, or give them either the first or the last appointment of the day.
- Make sure that visiting hour restrictions do not apply to carers.
- Provide a bed or chair for carers or family members so they can stay overnight if needed. If the patient receives food and drink, offer the same

to their carer or family member.

- Treat people with intellectual disabilities – and their families and carers – with dignity, kindness and respect.

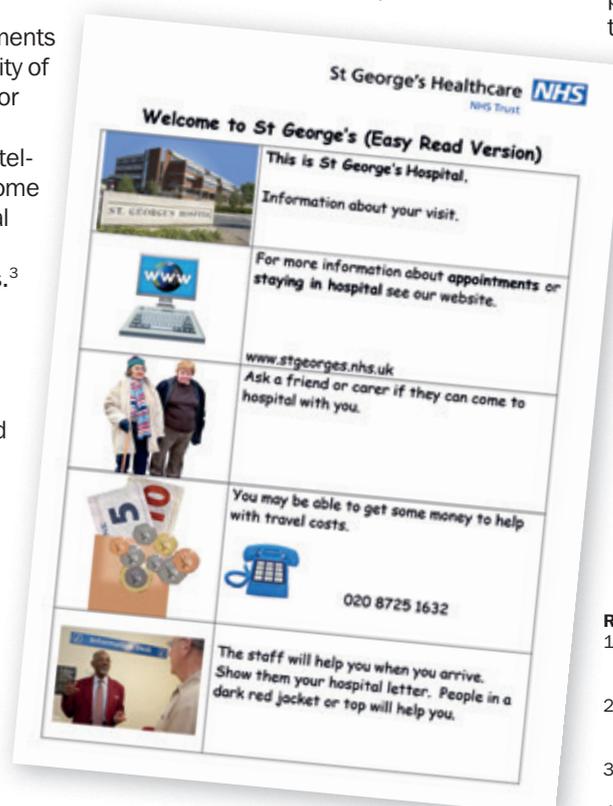
Communication

- Always speak to people with intellectual disabilities first, not the person supporting them. Take time to listen to their response.
- If they have difficulty answering questions then ask the person supporting them – but remember they may have different views from each other.
- Introduce yourself and explain your role: give your name and speak clearly, in short sentences, and not too fast.
- Communicate with the person with an intellectual disability by using visual aids (such as illustrations, photographs, pointing to objects), and using clear and simple language. Do not use abbreviations or jargon!
- Always explain at each stage of the examination or procedure what will happen next. People with intellectual disabilities do not like surprises.
- It may be helpful to create 'easy read'⁴ guidance to the hospital and common procedures (see illustration); these are written very simply, in a larger font, and accompanied by clear pictures (one picture or symbol per idea). This will save time in future.

Environment

- Make sure that lighting is not too bright or intrusive.
- Sudden noise can be very stressful. Keep noise to a minimum, or take the patient to a quieter area. Noise (announcements, television, or radio) can be very distracting.
- Keep the environment clean and tidy. Too much clutter can distract people and make it difficult for them to visually focus on you.
- Make sure that people know where the bathroom facilities and waiting room are, and that these areas are well signposted.

Compiled by Elmien Wolvaardt Ellison



'Easy read' information for people with an intellectual impairment. UNITED KINGDOM

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Community-based rehabilitation: working in partnership with eye care



Joerg Weber

Research fellow: International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, UK.

Community-based rehabilitation (CBR) was introduced in the late 1970s as a new approach to providing rehabilitation services at community level.

Over the years, the concept of CBR has widened to include much more than just medical rehabilitation. These days, organisations providing CBR aim to empower people with disabilities to enjoy education, health, and wellbeing, and to participate fully in social, cultural, civil, and political life. They do this by offering support to people with disabilities and by supporting projects – such as income-generating projects – in which people with disabilities can take the lead. This stimulates local initiatives and encourages self-determination.

The benefits of linking eye care workers and CBR programmes

Any response to the needs of people with visual impairment and their families will be more effective if eye care workers and CBR programme staff can work together at the community level.

Eye care services play an important role in identifying people with visual impairment and addressing their initial requirements, including treatment. However, many people with visual impairment may never come to the eye clinic! They may face a range of different barriers, including physical, economic, and attitudinal barriers. For example, they may be unaware of what is available, they may believe that they cannot afford eye care, or perhaps physically getting to the clinic is difficult for them.

To improve the coverage of eye services, eye health workers can train CBR workers to refer or even undertake basic screening in the communities they regularly visit. This way, eye care services will be provided to a greater number of people. CBR workers should also attend clinics held by the eye health services. This way they can better ensure that necessary follow-up visits or treatments take place, and that the family of the patient remains informed and motivated about medical or rehabilitation procedures.

The importance of CBR referrals

Eye care workers can refer people with low vision or other visual impairments to a CBR programme. This is very important in order to assist a person with visual impairment to retain good levels of function and independence.

Because they can utilise their networks and take a holistic approach to patient care, CBR projects are efficient hubs for obtaining referrals and other support or action on behalf of patients and their carers. This can help people with visual impairments to overcome a multitude of barriers to inclusion in the community at all levels in society, and at different stages in life.

CBR can support eye care delivery in the areas of health, education, livelihood, society, and empowerment. The following are possible further steps for each of these at community level.

Actions for health

- Promote eye health by creating awareness (how to recognise signs of visual impairment, the need for early detection, information about low vision aids, medical procedures, etc.).
- Refer people with suspected visual impairment for further testing and follow-up examinations.
- Advocate for appropriate low vision services at health centres and hospitals as close to the community as possible.
- Inform children and adults with visual impairment, their family members, and the general public about available options for the inclusion of people with visual impairment in the community.

Actions for education

- Facilitate educational opportunities for

children and students with visual impairment at all pre-primary, primary, secondary and higher levels of education.

- Educate teachers in regular schools about the impact of visual impairment and the provision of an effective learning environment for children with visual impairment. Encourage the inclusion of these topics in teacher education programmes.
- Ensure that families of children with visual impairment understand the practical implications of local policies relating to the education of such children.
- Recruit and train people with visual impairment as CBR workers and teaching assistants.

Actions for livelihood

- Ensure that people with visual impairment and their families are fully aware of their rights with respect to employment.
- Ensure that people with visual impairment have access to social protection mechanisms such as social security.
- Advocate among trade unions and employers to promote inclusion of people with visual impairment.

Actions for society

- Help to reduce stigmatisation of people with visual impairment.
- Raise awareness in the community of the causes and nature of, and possible solutions, for visual impairment.
- Help to ensure that people with visual impairment have access to all cultural, recreational, sport, religious, and other activities in the community.

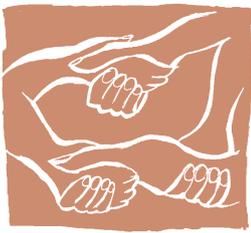
Actions for empowerment

- Support the establishment of local support and self-help groups for people with visual impairment
- Hire and train people with visual impairment as CBR workers and in primary health care.

Two-way referrals and close networking between eye care and CBR will significantly improve medical, educational, economic and social outcomes for people with visual impairment and their families.



Fieldworkers conducting simple vision tests, showing how CBR can support detection and referral. MALAWI



Fire safety in the eye theatre

**Brian R Savage**Ophthalmologist, Mvumi Hospital,
Dodoma, Tanzania

Recently while doing cataract surgery, I saw a visiting student wandering across our theatre unaware that he was trailing flames from his gown. Deserting my patient, I beat on the back of the unsuspecting student with my surgically gloved hands (!) to put out the flames. The student was not harmed except for a hole in his gown, though my hands were a bit scorched, and the seeds of this article had been sown.

Fire in the eye theatre is, fortunately, a rare occurrence. Should there be an outbreak of fire, however, there is serious risk of injury to patients, who because of blindness and age may be less able to make a quick escape, also to staff and students, especially at times of greater risk (e.g. if the theatre is busy and crowded).

The three theatre fires of my experience have all been due to the use of a methylated spirit lamp as a low-cost means of heating cautery. Although economical, the method has a number of disadvantages:

- The 70% aqueous spirit usually available is difficult to ignite, consuming time and many matches.
- Therefore once burning, the naked flame may be left burning for the duration of a list.
- If the burning lamp is placed near a window, the burning flame may not be visible in the light
- If placed (as is common) on a low stool in the centre of the theatre, near to the instrument nurse, the lamp is just at the right height to ignite a low-hanging drape, or the folds of the operating gown, or clothes, of staff or students who are passing by, or who are leaning over, engrossed in the progress of an operation.

Spirit lamp fires are easily preventable:

- If possible, do not use them in the first place. Use an alternative method which can be switched on and off easily, notably a cheap cigarette lighter,¹ or a battery-driven or mains powered electrical cautery machine. Electrical cautery however tends to be more expensive, and require special precautions to make sure of sterility.
- If for some reason there is no alternative, then the lamp must only be ignited at the precise time when required, by an assistant for whom this



This spirit lamp is alight, but the flame is hardly visible in the bright light, coming from a window nearby.



Lighted spirit lamp on a low stool very close to the gown of a scrub nurse attentive only to the operation.



Inexpensive cigarette lighters of a type available locally can be ignited and extinguished easily and safely.



Any bucket will do as long as it can be easily lifted by any member of staff.



Dry powder fire extinguisher. Note the white pointer on the dial is in the green (safe) range. Check it annually with the fire department.

is the sole responsibility, and the flame should be extinguished **as soon as** cautery has been performed.

Other sources of theatre fires include:

- electrical faults
- fuel such as gas or kerosene for stoves used in instrument sterilisation, or petrol used in a generator.
- use of a naked flame in the vicinity of gaseous oxygen used for anaesthetic purposes.
- spent matches thrown inadvertently into waste material while still alight.

Prevention is not difficult, and I suggest the following:

- 1 Have a meeting with staff to inform them about, and discuss with them, the dangers of fire in the theatre.
- 2 Draw up (jointly) a set of simple rules for preventing fire, and also what to do if a fire starts.
- 3 Mark emergency exits in the theatre, and make sure they can be easily opened if there is a fire. If they are locked, the **key must be available in the door.**

- 4 Have a bucket of water and/or sand and fire extinguishers present in the theatre. Make sure staff know how to operate fire extinguishers and have the extinguishers checked and refilled annually or after use.
- 5 Do not have a naked flame in the presence of anaesthetic oxygen.
- 6 Keep fuels such as gas, kerosene or petrol, and equipment using these fuels, outside the theatre. They should be used in a well-ventilated room with an escape route in case of fire.
- 7 **Always** turn off stoves or generators **before** refilling, **never** refill while they are still running.
- 8 Know where electrical appliances and mains power can be switched off in case of an electrical fire or fault.
- 9 Get an electrician to check the safety of the theatre electricity supply.

Finally it is worth examining the hospital insurance policy to see whether harm to patients, staff and equipment is covered if a fire took place in your eye theatre.

Reference

- 1 Savage BR. Using a lighter to heat a cautery. *Comm Eye Health J* 2011;24(75): 23.

Management of an eye prosthesis or conformer



Sue Stevens
Former Nurse Advisor, *Community Eye Health Journal*, International Centre for Eye Health, London, UK.

You will need

- Small pot of saline or cooled boiled water
- Mirror
- Cotton buds
- Gauze swabs
- Prosthesis (artificial eye) or conformer (shell)

Before you start

- Provide privacy so that the patient can practice this procedure without others looking on.
- Encourage the patient and reassure them that the procedure, although perhaps difficult at first, will become easier for him/her to manage alone.
- Patients may wish to observe, by using a mirror, someone performing this procedure on them before attempting removal and insertion by themselves.
- Encourage patients to look at and feel the empty socket. They may be fearful of doing so, and this is often the main challenge in building confidence for self-care.

Inserting the prosthesis or conformer

It will help if the patient looks **downwards**.

- 1 Clean the eyelids using cotton buds or gauze moistened in saline.
- 2 Take the prosthesis or conformer and moisten in the saline (Figure 1).
- 3 Hold the prosthesis or conformer between the thumb and forefinger with

Murray McGavin

Figure 1

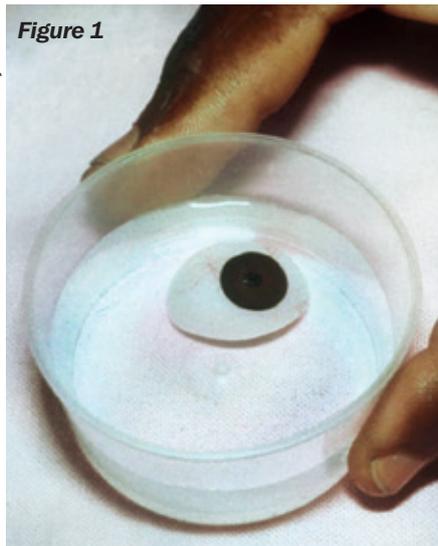
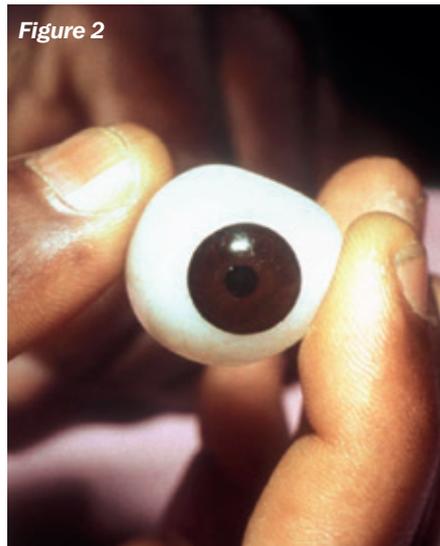


Figure 2



the indentation uppermost and the convex surface outermost (Figure 2).

- 4 Using the other hand, gently lift the upper eyelid with a fingertip (Figure 3).
- 5 Insert the upper part of the prosthesis or conformer under the eyelid in an upwards, backwards and inwards movement (Figure 4).
- 6 Remove the hand from the upper eyelid (but still support the prosthesis or conformer) and, with the free hand, gently pull down the lower eyelid. The lower part of the prosthesis or conformer should then slip easily into place inside the lower eyelid (Figure 5).
- 7 Check that normal eyelid closure is possible and, importantly, comfortable for the patient.

To remove the prosthesis or conformer

It will help if the patient looks **upwards**.

- Clean the eyelids using cotton buds or gauze moistened in saline.
- Using an index finger gently pull down the lower eyelid in order to see the edges of the prosthesis or conformer.
- Gently push the eyelid under the prosthesis or conformer and, with the other hand, exert some fingertip pressure on the upper eyelid. The prosthesis or conformer should slip out easily into the cupped hand (Figure 6). (The picture shows the patient doing this himself.)
- Place the prosthesis or conformer in the saline. It should be cleaned thoroughly before re-insertion.

Murray McGavin

Figure 3



Figure 4



Murray McGavin

Figure 5



Figure 6



Inspecting and unbending surgical needle holders



Ismael Cordero
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A needle holder, also called a needle driver (Figure 1), is made from stainless steel and is used to hold a suturing needle during surgical procedures.

To maintain a firm grip on the needle, the jaws have textured patterns either etched directly on the stainless steel or on a replaceable tungsten carbide insert, which grips the suture needle more precisely and wears out much slower than stainless steel. Needle holders with tungsten carbide inserts are normally identified with gold plated rings.

A needle holder must be matched to the needle size for which it is intended.

Post-operative care

Open the needle holder by separating the ratchet. Prevent blood from drying onto the instrument by soaking it in an enzymatic solution. Alternatively, place a moist towel saturated with water over it within 20 minutes of use.

Inspection and testing

A needle holder should be able to hold a hair on the back of your hand. If not, it is not functioning properly. With use, the jaw surfaces will wear out and stop making full contact, which affects their grip. Bends and cracks can also develop on the jaws and other parts of the needle holder.

It is important to inspect needle holders after each procedure and before sterilising them. Use a bright lamp and a magnifying glass or microscope to check for any of the following flaws.

- **Bent or worn jaws.** When the needle holder is held up to a bright light in the closed position, no light should shine through the jaw surfaces. If the light only shines through a small portion of the jaws, either the jaw or the jaw insert is worn out. A worn jaw insert must be replaced by the manufacturer or a qualified vendor. If the jaw is worn (Figure 2), the entire needle holder must be replaced. If the light shines through a significant portion of the surface (Figure 3), one of the jaws is probably bent. Follow the procedure described later in this article to correct it.

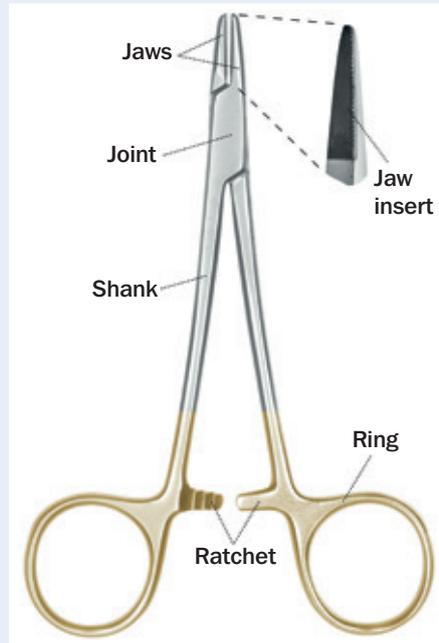


Figure 1. The main parts of a needle holder. The handles consist of a shank, a ring, and a ratchet mechanism that locks the needle in place.

- **Cracks in the jaws or joint.** Even small cracks compromise the integrity of the instrument. This means it should be sent to the vendor or manufacturer for repair.
- **Cracks in the jaw inserts.** The majority of insert damage occurs at the tips. The insert must be replaced if cracks are seen. If the tip of an insert looks and feels significantly less coarse than the rest of the insert, it should be replaced.
- **Rust and stains.** In order to determine whether a brown or orange discoloration is rust or a stain, rub a pencil eraser aggressively over part of the discoloration. If the discoloration cannot be removed and if there are pit marks, then it is rust and requires soaking in a rust removal solution and/or brushing carefully with a

brush. If it can be removed and the metal underneath is smooth, then it is a stain and it can be removed by soaking in a stain removal solution.

- **Loose joint.** Open the instrument, grab one ring handle in each hand and gently push one handle up and down. There should be some give-and-take in the instrument, but if it feels too loose it should be repaired.
- **Poor ratchet fit.** Check that the jaw tips close in the first ratchet position and that the entire jaw closes in the third ratchet position. If a needle held in the jaws of a needle holder can be easily turned by hand with the instrument locked in the second ratchet position, repair is needed.

Preparing for sterilisation

If any dried blood or discoloration is discovered on the needle holder, the instrument must be cleaned prior to sterilisation. Needle holders should always be sterilised with the ratchets disengaged.

Correcting bent instruments

Bent needle holders can sometimes be corrected using a pair of flat-tipped pliers using the steps below. (**Note:** these procedures should **not** be used for needle holders with tungsten carbide inserts since they are brittle and can fracture easily.)

- 1 Close the needle holder, and look at it from the side. If you notice that the jaw tips are not aligned (Figure 4), then at least one tip is bent and you can try to straighten it with flat-tipped pliers (Figure 5). If it is not obvious which tip is bent, you can take turns bending both tips so that they align. **Note:** do not use too much force; bend the tips little by little.
- 2 Close the needle holders completely and hold them against a light. If light shines through the jaw surfaces (Figure 3) then you will need to bend one or both of the jaws towards each other.
- 3 If the ratchets do not hold anymore, bend the handles towards each other.
- 4 After unbending, test the needle holder by grabbing a hair on the back of your hand – the hair should not slip out.



Figure 2

Ismael Cordero

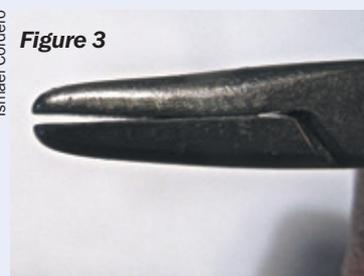


Figure 3

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Figure 4

Ismael Cordero



Figure 5

Ismael Cordero

Sources

- 1 Haddad D, Worst JGF. Standard operating procedure manual for the maintenance and repair of micro-surgical instruments. 1992. <http://tinyurl.com/cwao386>
- 2 Schultz R. Inspecting surgical instruments, an illustrated guide. 2005; Stow, OH: RMPS Publishing.

Children as agents of change in trachoma control



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Trachoma is the leading infectious cause of blindness worldwide. Despite the fact that trachoma is preventable, 7.2 million people suffer from trichiasis, the potentially blinding stage of trachoma, and 325 million live in areas where trachoma is confirmed or suspected. According to the World Health Organization, 21 million people have trachoma (Weekly Epidemiological Record No. 17, 27 April 2012).

This situation requires immediate action if the global target to eliminate blinding trachoma by 2020 is to be reached.

The WHO endorses the SAFE strategy to prevent and treat trachoma. **S**urgery treats trichiasis patients, **A**ntibiotic distribution treats active infections, and **F**acial cleanliness and **E**nvironmental sanitation prevent the transmission of trachoma.

In Ethiopia, the country with the heaviest known burden of trachoma cases in the world, health educators promote the SAFE strategy in a range of different settings.

Schools are an ideal place to target children, who are most susceptible to trachoma infection. In 2005, the Carter Center began health education in 700 schools in the Amhara National Regional State. Teacher training was scaled up in 2008 and 2009, following the expansion of the programme to cover the entire region. In total, 7,822 primary schools now have ongoing health education.

The Carter Center trained one science teacher and the director from each primary school to implement the trachoma primary school curriculum developed jointly by The Carter Center and the ministry of health. In a recent assessment of school-based activities, we found that school children supported the SAFE strategy in several key ways.

- **Children can help to identify family members who have trichiasis.** Teachers instructed children to go home and ask whether any family member had 'hair in the eye.' Children asked their family members if they knew what caused the condition. Common myths included that trichiasis was the result of a curse or the fault of the individual.
- **Children can educate family members about trichiasis.** The children, empowered with information

from their teacher, explained that trichiasis is caused by a disease and is not their fault. Children's views were generally respected by their family, who were proud to have a child who is attending school.

- **Children can support mass drug administration campaigns.** They can do so by participating themselves and by encouraging family members to take azithromycin.
- **Children can learn improved hygiene habits.** In schools where water is provided and where there is sufficient health education and mobilisation, children can learn to practice good facial cleanliness and help to monitor the facial cleanliness of other children. In addition, they can care for younger siblings and can be encouraged to clean their faces for them.
- **Improved sanitation.** At school, children learn how to use latrines and how these latrines can prevent diseases like trachoma. Health clubs at some schools teach students about healthier

hygiene habits and how to prevent trachoma. Health, trachoma, and environmental sanitation clubs help to organise environmental sanitation campaigns at school and in the community. We also met children who had convinced their families to construct latrines at home.

Healthy habits that children learn in school improve their health and the health of their families and future generations. Children in secondary schools are particularly effective at educating families and encouraging behavioural change in their families, such as keeping faces clean and using latrines. Older school children are the parents of the immediate future who will raise their families with healthier habits and they should receive targeted trachoma health education. For all children, school-based health education in addition to other forms of health education – such as radio messages, health extension workers, and social organisations – collectively work to demystify trachoma, reduce stigma and shame, and to prevent blindness.

Case Study: Iyasta Primary School

The students and staff of Iyasta Primary School in Ankasha Woreda district played a unique role in promoting health education and the SAFE strategy in their community. In this district, people have resisted taking azithromycin during the twice-yearly MalTra Week campaign. This campaign distributes eye ointment containing azithromycin and tetracycline to half of the people in the Amhara National Regional State in Ethiopia in May, and to the rest in November. Primary school children, themselves initially reluctant to take the drug, were educated by the local health extension workers about the transmission, progression, and prevention of trachoma. The children then encouraged their parents to take the drug, resulting in a 60.4% increase in coverage compared with the previous year. People noticed that the signs and symptoms of trachoma and other diseases resolved after taking the drug and now request azithromycin.

The following conditions supported



S. Ogdery/ITI

Students learn both in classrooms and outdoors when there is insufficient classroom space. ETHIOPIA

the success of mobilising students to assist with the MalTra campaign.

- Routine supervision and a post-MalTra Week review meeting identified that the area had low coverage in time to intervene before the next campaign.
- The health workers in the area already had a relationship with the school and were motivated to go and speak with the school staff.
- School staff were willing to assist, and allowed class time for health extension workers to speak with the children.
- The health education delivered by the health extension workers was effective enough to convince children to take the drug and speak to their families.



Test your knowledge and understanding

This page is designed to test your understanding of the concepts covered in this issue and to give you an opportunity to reflect on what you have learnt. The multiple true/false questions were produced in collaboration with the International Council of Ophthalmology (ICO) and the Diagnose This quiz is provided courtesy of the Ophthalmic News and Education (ONE®) Network of the American Academy of Ophthalmology.

| 1. Think about your understanding of disability and impairment | | True | False |
|--|--|--------------------------|--------------------------|
| a | People with impairments face barriers such as small print they cannot read, or stairs they cannot climb | <input type="checkbox"/> | <input type="checkbox"/> |
| b | It is helpful to show pity for people with impairments | <input type="checkbox"/> | <input type="checkbox"/> |
| c | The words 'disability' and 'impairment' mean more or less the same thing | <input type="checkbox"/> | <input type="checkbox"/> |
| d | It is better to talk to the person supporting someone who is visually impaired, rather than the person themselves | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Think about how to be more inclusive of people with impairments | | True | False |
| a | When you update your facilities, involving architects, eye care specialists and disabled people's organisations is the best way to get a 'Design for All' result | <input type="checkbox"/> | <input type="checkbox"/> |
| b | One of your colleagues thinks that women with disabilities have committed sins and are evil. This attitude negatively impacts on their work, but nothing can be done about it | <input type="checkbox"/> | <input type="checkbox"/> |
| c | The best way to find out how accessible your eye service is for people with impairments is to ask users with impairments, for example with a 'knowledge, attitudes, practices' (KAP) survey | <input type="checkbox"/> | <input type="checkbox"/> |
| d | Regularly inviting representatives from disabled people's organisations into your hospital for news/advice will help your patients receive the most effective and inclusive services | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Think about the needs of people with different types of impairments | | True | False |
| a | It is best to find out what a patient with a hearing, mobility, or intellectual impairment may need before they arrive at the clinic | <input type="checkbox"/> | <input type="checkbox"/> |
| b | You have several medical issues to discuss with your patient. They nod in agreement with all your suggestions. You can safely assume that they have understood everything you have explained | <input type="checkbox"/> | <input type="checkbox"/> |
| c | You guided a patient with a visual impairment by pulling them along with you and then leaving them in the centre of the next waiting area. There are better ways you could have handled this | <input type="checkbox"/> | <input type="checkbox"/> |
| d | Patients need both verbal (spoken) and written instructions to ensure they take the correct drugs at the correct time once they leave the clinic | <input type="checkbox"/> | <input type="checkbox"/> |

ANSWERS

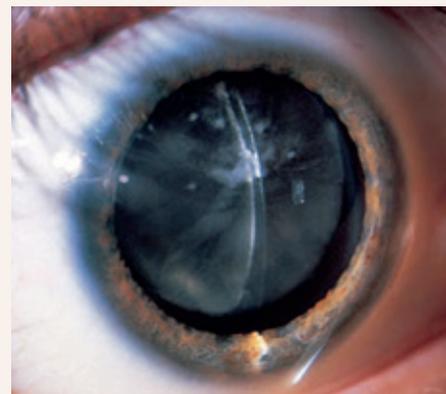
1a. True; b. False; c. False; d. True. People with impairments do not like to be pitied. It is better to treat them with the same respect and dignity you would show to people without impairments. c. False. Impairments refer to the physical or intellectual problem, such as hearing, visual, intellectual, or mobility impairments. People with impairments are disabled when society does not include them by making services or goods accessible to them. d. False. Always talk to the patient directly, no matter what impairment they have, or who else is in the room.

2a. True. Involve as many as possible of the groups affected, especially people with impairments. This will bring you closer to full inclusion. b. False. Training about disability discrimination may help, however, it will take more than one training session to challenge entrenched beliefs and core discriminatory attitudes. c. True. See Comm Eye Health J 2012;25(78):22-24. d. True. Remember, people with actual experience of disability are the experts!

3a. True. This can be done by telephone, mail, or via an outreach health worker. Doing so will help both you and the patient to prepare for the visit, for example by arranging a sign language interpreter. b. False. It may be that the patient has a hearing impairment or a learning difficulty, or simply that they are not confident to ask questions or challenge you. c. True. Offer your arm so they can hold on to it while you walk. Explain what you are doing and where you are, and guide their hand to the back of a chair if they have to sit down and wait. d. True.

Diagnose This quiz

A patient presents with a cataract and lenticular changes as shown. Which of the following is the most likely cause of his cataract?



- Atopy
- Electrical injury
- Myotonic dystrophy
- Chronic use of topical steroids

ANSWER

The most likely cause is electrical injury

Electrical injuries, such as those associated with high-voltage electrocution, cause coagulation of lens protein and give the typical cortical-spoking lenticular changes displayed in the figure. Approximately 90% of all patients with myotonic dystrophy develop cataracts. In the early stages, the cataract presents as a diffuse opacification of the posterior subcapsular region. Later, the opacification becomes dense and often produces a stellate lesion at the posterior pole. Patients using corticosteroids for chronic conditions commonly present with posterior subcapsular cataracts. Patients with atopy generally exhibit anterior or posterior capsular cataracts, often with stellate opacification.



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Primary open-angle glaucoma: reader feedback

Thank you to everyone who commented on our double issue on primary open-angle glaucoma (Comm Eye Health J 2012;25(79&80).

John Sandford-Smith (UK) pointed out both an error and an omission. In 'Detecting possible glaucoma with only limited equipment', the last sentence of section 6 (page 49) reads: 'Remember. A RAPD is not only caused by a cataract.' In fact, a cataract in an otherwise healthy eye **never** causes a RAPD. Apologies both to the authors and our readers for

the error, which occurred during editing. The omission was in the panel about sub-conjunctival 5FU injection, on page 75, where no advice was given about dose strength and volume. In response, the article's author suggests a dose of 10 mg. If using 5FU at a concentration of 50 mg/ml, the volume injected would be 0.2 ml.

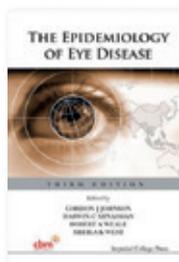
Daniel Laroche (USA) disagreed with the statement that IOP below 21 is 'normal': 'There is good evidence that the mean normal IOP is 15 and the mean glaucoma IOP is 18. When I see patients with IOP of 17–19 I look carefully at their nerve fibre layer to ensure there is no early glaucoma.'

Finally, **Hugh Taylor (Australia)** suggested that more emphasis should be placed on the the family history of glaucoma: "A family history of glaucoma will increase the chances of developing glaucoma up to eight times. This has a far bigger impact than any other known risk factor. We have to work hard to make sure that all patients with glaucoma inform their relatives. When we are examining patients in general, we must also specifically ask them about their family history."

The letters are available in full on www.cehjournal.org

NOTICES

Book review



The Epidemiology of Eye Disease, 3rd Edition, edited by Johnson GJ et al.

The third edition of this authoritative text is 240 pages longer than the previous version and has 15 additional

expert contributors. There is an extra chapter on research synthesis and an expanded section on visual impairment and blindness in children. Dry eye and uveitis now feature as separate entities, and the final two chapters address the practical application of epidemiology in changing people's lives for the better. (Reviewed by Nick Astbury.)

Cost: UK £98. Readers can quote **WSOPH** to get a 50% discount when ordering from: World Scientific Publishing (UK) Ltd., c/o Marston Book Services, PO Box 269, Abingdon, Oxon OX14 4YN, UK. Email: direct.orders@marston.co.uk

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For information on courses, contact Genes Mng'anya, KCCO Tanzania Limited PO Box 2254, Moshi, Tanzania. Tel: +255 27 275 3547. Visit www.kcco.net

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Next issue



The next issue of the *Community Eye Health Journal* will be on **Neglected tropical diseases**