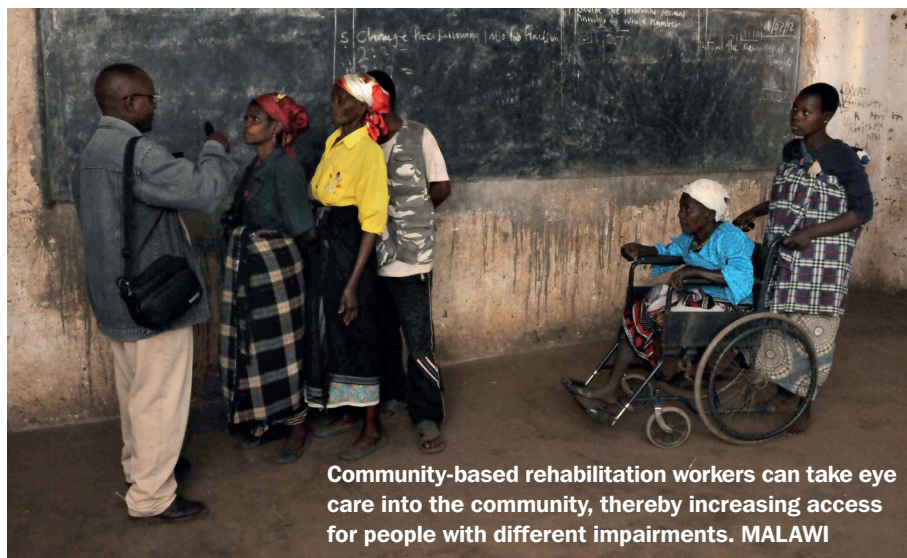# Facing up to disability

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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

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

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 artices 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!

In this issue

EDITORIAL *Continued*

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.

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.

What does it mean to have an impairment?

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

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

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 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 a 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