

INCLUSION MADE EASY IN EYE HEALTH PROGRAMS

Disability inclusive practices for strengthening comprehensive eye care





Front cover and above – photos and story: CBM, Cambodia.

Following successful eye surgery at the disability-inclusive Caritas Takeo Eye Hospital, Sokah was referred to other services for support with his deafness and speech barriers. Sokah left the hospital with the ability to see and is enrolled in school for the first time. He now receives Community-Based Rehabilitation to foster his inclusion at school and support his speech development. His mother, Nget, has also been able to return to work to improve their family's income. For more information on Sokah and his story, see page 94.



CBM is a leading international development organisation focused on disability inclusion in poorer regions of the world. CBM seeks to build and promote an inclusive world in which all people with disability enjoy their human rights and achieve their full potential. CBM is a founding member of VISION2020 and active in the prevention of blindness, together with other impairments causing disability.

This guide can be downloaded at: cbm.org/disability-inclusive-eye-health
Translations will also become available.

FOREWORD

People with disabilities constitute the world's largest minority group. As such, this 'guide' is a very important resource for all people working in eye health. It addresses the specific steps needed to ensure people with disabilities have equal access to eye health programs, and also the need to ensure that those with permanent vision loss access wider opportunities.

The 'VISION 2020: The Right to Sight' global initiative was launched in 1999 to promote and develop a global momentum to reduce avoidable blindness. The governments of 195 countries have since signed the VISION 2020 declaration, showing their support to its objectives.

In the year 1995 it was estimated that there were 45 million people who were blind in the world, with 80% of this vision loss being avoidable. The 45 million figure was projected to increase by approximately one million people per year due to population growth and ageing, reaching 76 million by 2020. However, the latest estimates from the World Health Organization for 2010 indicate there are 39 million people who are blind, which is 19 million fewer than projected before the VISION 2020 initiative. Much of this success can be attributed to VISION 2020, with improvements in human resource development, infrastructure and interventions.

While we have seen considerable success in addressing the primary causes of avoidable blindness – cataract, trachoma, onchocerciasis (river blindness), vitamin A deficiency and refractive errors – there remain significant issues that Community Eye Health programs face. These include lack of resources, the need for better integration of eye care into general health care, how to address at community level the emerging problems of glaucoma and diabetic retinopathy, and how to ensure access and opportunities for all members of communities.

Collectively, we need to find solutions to these issues so that all people who are under-served benefit from the momentum created by VISION 2020.

This guide seeks to address two important questions facing all eye care personnel, namely:

How to make eye care services accessible and inclusive for people with disabilities.

People with disabilities make up 20% of the world's poorest people. Eye care providers need to make sure that their services are inclusive and accessible to persons with sensory, physical and intellectual impairments, as well as those with mental health conditions.

And...

How to assist people with permanent vision loss whose sight cannot be restored.

At least 20% of people who are blind or have severe vision loss cannot have their sight restored. It is important that eye care personnel know how to assist people with vision loss, and how to enable them to receive appropriate mobility, living skills, education, rehabilitation and livelihood opportunities.

It is our pleasure to congratulate the authors and supporting organisations on the production of this practical and important guide. We hope that its principles of disability inclusion will be widely adopted and applied.



Bob McMullan

*President, International Agency
for Prevention of Blindness (IAPB)*



Professor Allen Foster, OBE

*President, CBM (2006 – June 2013)
Co-director, International Centre
for Eye Health, London*

Glossary

CBR	Community-Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Peoples Organisation
IDDC	International Disability and Development Consortium
ME&L	Monitoring, Evaluation & Learning
NGO	Non Government Organisation
OPD	Outpatient Department
PBL	Prevention of Blindness
PHC	Primary Health Care
RACS	Royal Australasian College of Surgeons
VHW	Village Health Worker
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization

Acknowledgments

Many hours of research and expertise have gone into the development of the *Inclusion Made Easy in Eye Health Programs* guide. We are grateful for the contribution of many eye health and disability practitioners worldwide, in particular, the work of many people in CBM and its field partner organisations, the CBM-Nossal Partnership for Disability Inclusive Development in Australia, members of Vision 2020 Australia and their field partners and all our co-branding agencies, together with other groups and individuals.

We would also like to acknowledge the Australian Government's support for the former edition of this guide under the Avoidable Blindness Initiative – supported by the Australian Agency for International Development, AusAID.

For more detailed acknowledgments, please see page 100.

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Photo: CBM, Nigeria

Independent skill development following diagnosis of a permanent eye condition –

Harira, with her father Abdullah, attended an eye hospital in Nigeria where they discovered her condition was untreatable. The hospital provided supportive counselling to father and daughter, and arranged referral to an active rehabilitation program that will assist Harira to continue at school and develop in other parts of her life in her community. Thanks to this referral and the support of her loving family, Harira can make the most of her limited sight.

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Overview

This *Inclusion Made Easy in Eye Health Programs* guide provides important, practical information on how to include all people with disability, including those with vision impairment, in eye health programs. It offers an overview of disability from a rights-based perspective along with current concepts and evidence of disability inclusion within the international development context. People with disability represent the largest minority group worldwide; therefore, the prevalence and impact of disability within developing countries is identified in this guide, along with the cycle that exists between poverty and disability. Inclusive practices, practical approaches and examples related to embedding disability inclusion in eye health programs are also illustrated throughout this resource.

What is the purpose of the *Inclusion Made Easy in Eye Health Programs* guide?

This guide has been produced to support and build upon the existing high quality disability inclusion efforts of eye health practitioners in developing countries worldwide. Its purpose is to encourage access, best quality outcomes and improved quality of life for anyone in need of eye care services, no matter what their medical prognosis may be or what other impairments they may have. In addition, principles throughout this guide are transferable and will be of relevance to other health sector programs.

Who is this guide for?

This guide has been prepared for staff working at all levels of eye health programs. As much of the content is transferable to other health sector programs, the guide will also benefit other practitioners within the broader health sector. This guide offers quick access tools and practical case studies in an easy-to-read format. This ensures that disability-inclusive practices can be readily embedded into eye health programs. Information and strategies for disability inclusion (including awareness raising, policy development, planning and practical processes) are incorporated within a human rights framework throughout this guide. It is intended that this guide will also be available in a range of other languages. Check cbm.org/disability-inclusive-eye-health for translations as they become available.

What does the guide seek to answer?

This guide responds to people with disability as the world's largest minority group and answers the questions around how eye health programs can remove disability-related barriers. The additional steps required for inclusion of women, children and older people with disability are also identified throughout this resource. Finally, strategies for those presenting with a permanent eye condition for which there is no treatment are also included.

What are the key features of disability-inclusive practice covered in this guide?

In accordance with the human rights model of disability, the inclusive practices of Awareness, Participation, Comprehensive Accessibility and the Twin-Track approach are embedded throughout this guide. In addition, strategies for improved disability inclusion within services such as counselling, referral processes and networks, rehabilitation and training are emphasised, alongside recommendations for increased gender equity and quality child protection processes.

How to use this guide

This guide is divided into seven sections. Embedded across the guide is a focus on principles and processes for disability inclusion in eye health programs. The guide is not meant to be read in its entirety as individual sections may be more relevant than others. Importantly, each section is designed as a self-contained chapter with key messages, an overview of relevant inclusive approaches, sector examples, a checklist and useful resources. For this reason, some messages are repeated as they relate to different aspects of eye health programs. Readers may also find particular content (such as case studies and checklists) of greatest relevance to their own role in ensuring eye health programs are disability inclusive. As the guide offers a general overview of disability inclusion, eye health program and other health sector staff are encouraged to adapt relevant information to target the work within their context.

Feedback

The *Inclusion Made Easy in Eye Health Programs* guide reflects a current gathering of principles and experiences of disability-inclusive practices in eye health in lower income contexts of the world. This guide is part of the Inclusion Made Easy series and is a living resource. Suggestions for improvements are welcomed. Please send all comments, feedback, relevant case studies, learnings and requests for additional content to inclusionmadeeasy@cbm.org.au.

GETTING STARTED:

Ten practical steps for strengthening disability inclusion in eye health programs

- 1. The objective:** To ensure eye health programs are inclusive of people with all types of disabilities, including vision impairment, and that people with a long term vision impairment access their right to wider opportunities.
- 2. Awareness:** Raise staff and community knowledge about the rights and capacity of people with disability. Emphasise that one in five of the world's poorest people have a disability. Encourage positive attitudes and dispel possible myths about causes of impairments.
- 3. Participation:** Strengthen all aspects of your eye program through active engagement of people with disability and Disabled People's Organisations. Employ people with disability.
- 4. Disability Inclusion Officer/Disability Advisory Committee:** Appoint a Disability Inclusion Officer, which could be part of an existing staff member's job. Identify staff and community members to form a committee aimed at strengthening and maintaining disability inclusion across the program.
- 5. Disability inclusion policy:** Develop a policy for disability inclusion, linked with gender and child protection policies. Create a safe and welcoming environment for all patients, community members and staff on a daily basis.
- 6. Physical access:** Work with people with disability to identify and address all physical access barriers in program buildings, including the entrance, between departments, rooms, examination equipment and toilet facilities.
- 7. Communication:** Take extra steps to ensure written and spoken communication, including signage, brochures and announcements are accessible for all people. Consider especially the needs of people who have vision, hearing or intellectual impairments.
- 8. Financial barriers:** Address cost barriers of treatment, transport and accommodation for people with disability and others living in poverty, and accompanying person where relevant.
- 9. Referral and support networks:** Through advocacy, training and mutual learning, strengthen all your networks to become more disability inclusive. Increase your networks by including all mainstream and disability specific services such as Primary Health Care, Community Based Rehabilitation and education facilities, both government and non-government.
- 10. Blindness and low-vision services:** Ensure the 20% of people who are blind or have permanent vision loss, whose sight cannot be restored are supported with their families to receive counselling, are referred to low vision services, inclusive education, support for independent living skills, Community Based Rehabilitation, Disabled Peoples Organisations and mainstream livelihood opportunities.

section 1

UNDERSTANDING DISABILITY

Key messages

- ▶ Disability is present in all communities.
- ▶ A disability is created through a person with an impairment interacting with socially imposed barriers that in turn limit functioning.¹
- ▶ People with disability report multiple barriers to accessing health services,^{2 3} with these barriers being greater than for people without disability.⁴
- ▶ 15% of people worldwide are estimated to have a disability.⁵
- ▶ 22% of the world's poorest people in developing countries have a disability.⁶
- ▶ Only 2% of people in lower income countries, including those with a disability, have access to basic services and rehabilitation.⁵
- ▶ Identifying and overcoming barriers to accessing eye health is an important and practical way to build disability inclusion in eye health programs.
- ▶ Access barriers for people with disability, including those with a permanent eye condition, can relate to community attitudes, physical surroundings, financial limitations, communication, and laws and policies.⁷
- ▶ Many people with disability experience exclusion, stigma and discrimination, especially in relation to false beliefs about causes of impairment and the capacity of people with disability.⁸
- ▶ At least 20% of people who are blind or have severe vision loss cannot have their sight restored.⁹

Why include people with disability in eye health programs?

- ▶ People with disability are people first and have strengths, capacities and abilities to contribute to the development of their communities.
- ▶ People with disability form the world's largest minority group, and as a result eye health programs need to ensure services are inclusive and accessible to people with physical, sensory, cognitive, mental health and intellectual impairments.
- ▶ Eye health staff need to be skilled in responding to the minimum 20% of people with eye conditions whose vision cannot be restored, through supporting access to appropriate mobility, living skills, education, social inclusion, rehabilitation and livelihood opportunities.
- ▶ The United Nations Convention on the Rights of Persons with Disabilities (CRPD) explicitly highlights the rights of people with disability as valued members of their communities, with a particular focus on health in Article 25.¹⁰
- ▶ There is a strong correlation between disability and poverty, with poverty leading to higher prevalence of disability and disability increasing the risk of poverty.¹
- ▶ People living in poverty are more likely to acquire a disability due to unsafe living, work and travel environments, and less access to prevention efforts, treatment and rehabilitation services.¹¹
- ▶ People with disability such as a physical disability or hearing impairment are very dependent on their vision to support their independent living and therefore should be prioritised in eye health programs.
- ▶ Many people with disability have not had access to formal education and frequently miss out on livelihood opportunities, and can therefore be disengaged from community development processes. This further increases both the poverty and isolation experienced by people with disability and their family members.
- ▶ Women and girls with disability face triple discrimination: being female, having disability and being among the poorest of the poor.¹²
- ▶ Women and girls with disability are often at greater risk of violence, injury, abuse, neglect, maltreatment or exploitation.¹³

What is disability?

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes people with disability as having “long-term physical, mental, intellectual or sensory impairments that in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.⁹

There is an increasing recognition that the term *disability* does not simply refer to a medical condition but is rather the outcome of complex interactions between the functional limitations that may arise from a person's physical, intellectual or mental health condition or impairment, and their social and physical environment. Variation in understanding of disability reinforces that the lives of people with disability are made more difficult not so much by their specific impairment but rather by the way society interprets and reacts to difference in others.

Recognition of disability should include a human rights dimension. In doing so, there is acknowledgment of external barriers that result in social exclusion and increased vulnerability to poverty by people with disability.¹⁴ This idea is also identified by the World Health Organization's International Classification of Functioning, Disability and Health (ICF).



Photo: CTEH Cambodia, CBM

Disability access in eye health programs – A woman in Cambodia is able to access the eye testing facilities at Caritas Takeo Eye Hospital in a wheelchair. It is important that all facilities in eye health programs are wheelchair accessible. In addition to physical access, there are many other aspects that need to be addressed in order to achieve full accessibility for people with a range of disabilities. Without addressing physical and communication access along with attitudinal and policy barriers such as financial restrictions, people with disability will miss out on vital eye health services.

Models of disability

Historically, there have been a range of perspectives or models through which disability has been understood. The following list provides an overview of these models including the key features of each.

Charity model

Disability is viewed as an affliction and assumes a person with disability must be a recipient of care and protection. This approach tends to view the individual as passive and does not acknowledge the capacity of people with disability.

Medical model

The medical or biological model tends to emphasise the impairment or condition with a focus on treatment. Where the medical model is applied, the focus on impairment is often separate to considerations of social inclusion. In response, there is an effort to change what is 'wrong' with the individual in order to improve their inclusion. Some community members perceive disability through a medical model lens that can lead to people with disability not being valued unless they are 'fixed'. It is important to note that the term 'medical model' reflects impairment-focused thinking and does not refer negatively towards access to medical interventions. In fact, medical care and rehabilitation are an integral part of the rights of all individuals. People with disability should have equitable access to all health services, including high-quality eye care.

Economic model

The economic model tends to place value on people according to how productive they are. Through this view, disability can be seen as a strain on society if people with disability are viewed as less productive. Interventions are only justified when they make financial sense and economic strain is minimised.

Social model

This approach recognises that disability is created through an individual with an impairment interacting with socially imposed barriers. The social model places onus on removal of barriers in the environment so as to reduce the impact of an impairment. This approach recognises the right to medical intervention, including eye and other surgery, and to adaptive devices such as a white cane or wheelchair, alongside community access and participation through removal of external barriers.

Human rights model

The human rights model takes universal human rights as a starting point. People with disability are seen to have a right to access everything within their society on an equal basis with others. The rights-based approach incorporates social model thinking in which external barriers are addressed, in conjunction with the person with disability being the focal point in attaining their rights. The rights-based approach adopts awareness, participation, comprehensive accessibility and twin-track principles (disability-specific actions and mainstream responses) as core disability-inclusive development principles.



Photo and story: CBM, Paraguay

Fostering empowerment and inclusion – Twelve-year-old Jorge is learning to use a pair of binoculars for distance vision with Christian, an ophthalmic residency student from Bolivia. Jorge was born with a condition that affected his retinas. In his early years, Jorge was unable to attend school due to his vision impairment. Now, thanks to a low-vision clinic run by Fundación Visión in Paraguay, Jorge has received training in the use of low-vision devices, has reached third grade at school and is keen to continue his education. Jorge still attends the eye hospital and low-vision clinic once each month for ongoing support. The program Jorge attends is part of the VISION 2020 Latin American program, which has been very active in promoting and developing low-vision services. This has served as a very positive model for other regions around the world.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD)

In May 2008, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force. As of May 2014, the CRPD has been ratified by 147 countries and signed by 158 countries. This convention requires that people with disability have access to mainstream and disability-specific services with an emphasis on full and equitable inclusion. This convention affirms that the obligation for inclusion is placed on society rather than on people with disability.

The CRPD sets out general and specific obligations across 50 articles. Once nation states have ratified the convention, it provides a clear framework and set of entitlements for community members with disability, along with social obligations to achieve inclusion. In particular, Article 25 outlines specific rights to accessing high-quality health services, including those specifically relating to people with disability, along with requirements designed to minimise and prevent further disabilities. In addition, Article 32 relates to international cooperation to ensure international development activities, including eye health programs, are inclusive of and accessible to people with disability. Importantly, countries that have ratified the CRPD are obliged to include people with disability in accordance with human rights principles.

The Alma Ata Declaration

In 2008, Dr Margaret Chan, Director-General of the World Health Organization, called for a return to the principles of the 'Alma Ata – Health for All' declaration, produced at the International Conference on Primary Health Care, Alma Ata, Kazakhstan, in 1978. In calling for 'Health for All' and the strengthening of primary health care, this declaration reaffirmed the WHO definition of health being "a state of complete physical, mental and social wellbeing, and not merely the absence of disease". It also declared that access to health care is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal. For this to be realised, it requires the action of many social and economic sectors in addition to the health sector. The declaration also affirms that all individuals have the right and duty to participate in the planning and implementation of their health care.

This guide therefore considers the Alma Ata Declaration as an important reference point in promoting access to improved disability inclusion in eye health programs. Based on key principles in the Alma Ata Declaration, the guide affirms the following:

- ▶ If 'Health for All' is to be achieved in all sectors of the population, people with disability and their families need to be able to access eye care and other health services.¹⁷
- ▶ Primary Health Care (PHC) has an important role in ensuring that all marginalised people, including those with disability are able to access high-quality eye care.¹⁸
- ▶ The WHO definition of health being a state of complete wellbeing and not simply the absence of disease will only be achieved if all eye and other health programs recognise the wider role they have in ensuring that people with disability are able to access rehabilitation, education, livelihood and social opportunities.²⁰
- ▶ As for all members of the community, people with disability have both the right and duty to participate in the planning and implementation of their health care.²¹
- ▶ The principles of PHC can be used to support the attainment of wellbeing through full and proper integration of people with disability into mainstream society.

VISION 2020: The Right to Sight

Since its launch in 1999, the VISION 2020 movement has worked tirelessly to promote the rights of all people to access eye health and other related services.

The VISION 2020 principles that projects should be Integrated, Sustainable, Equitable and Excellent (ISEE) demonstrate strong synergy with disability-inclusive practices. This guide affirms these elements in accordance with the VISION 2020 principles.

Integrated: VISION 2020 promotes the integration of eye health activities into existing health services wherever possible. Disability-inclusive practice seeks good integration with other related services, designed to improve quality of life for people with permanent vision loss and other disabilities. These include services and opportunities in education, rehabilitation, livelihood and social inclusion.

Sustainable: A sound sustainability model for every individual will seek 'improved quality of life/whole of life' for people with permanent vision loss and other disabilities.

Equitable: Generally all eye care services seek to be available to the poorest and most marginalised people. To achieve this, people with all types of disabilities, including vision impairment, require accessible and equitable access. Achieving this often requires specific strategies to address physical, financial and community access barriers.

Excellent: Generally all eye care services seek to provide excellent clinical and non-clinical care. Excellence in disability-inclusive practice may include collecting adequate disability data to inform future services, access to individualised information, financial support in accessing services, counselling and support for people with disability, and referral to other appropriate services.

IAPB Hyderabad Declaration 2012

The IAPB Hyderabad Declaration of September 2012 affirms the inclusion of people with disability through the following goals:

- ▶ Goal 2 – An Inclusive International Developmental Framework is required to address blindness and vision impairment adequately.
- ▶ Goal 3 – Investments in Eye Health Structures, Human Resources and Initiatives are imperative to achieve access to eye health for all.



Photo and story: CBM, India

Self-help groups – Hulas (left) is the president of a local women's self-help group in India. She is one of many women with disability who demonstrate their strong capacity to contribute to the development of their communities and advocate for the rights of people with disability. Hulas has lost the functioning of her legs due to paraplegia and works with women with a range of disabilities, including vision impairment, to ensure inclusive and equitable access to health and other services within their community.

Checklist: Understanding disability

- ☐ Are all eye health staff aware of the high prevalence of disability in their communities?
- ☐ Are all eye health staff aware of the rights of people with disability?
- ☐ Do staff know the importance of social inclusion for people with disability?
- ☐ Are staff aware of the cycle of poverty and disability, where people with disability are at greater risk of living in poverty and people in poverty are at greater risk of acquiring a disability?
- ☐ Do staff recognise the difference between prevention of impairment and disability inclusion?
- ☐ Do staff understand causes of disability?
- ☐ Are staff aware of the importance of removing physical, communication, attitudinal, policy and financial-based barriers for people with disability?
- ☐ Do staff recognise that removal of barriers reduces the impact of an impairment?
- ☐ Are staff aware of the potential implications of false beliefs and myths that may be associated with disability?
- ☐ Is the eye health program aware of self-help groups and organisations designed to empower people with disability?
- ☐ Are key staff within the eye health program aware of all obligations under the Convention on the Rights of Persons with Disabilities?
- ☐ Does the eye health program adhere to the principles outlined in the Alma Ata Declaration?
- ☐ Are key staff responsible for ensuring appreciation of the VISION 2020 principles

Useful resources and websites: Understanding disability

Community-Based Rehabilitation: CBR Guidelines. (2010). World Health Organization.
www.who.int/disabilities/cbr/guidelines/en/index.html

Convention on the Rights of Persons with Disabilities. (2006). Geneva:
United Nations. www.un.org/disabilities/convention/conventionfull.shtml

Enable: Development and human rights for all. United Nations.
www.un.org/disabilities

Hyderabad Declaration. (2012). IAPB
www.iapb.org/9th-general-assembly/hyperbad-declaration

Inclusion Made Easy: A quick program guide to disability in development. (2012).
CBM. www.cbm.org/inclusive-development

International Classification of Functioning, Disability and Health (ICF). (2001).
World Health Organization.

World Report on Disability. (2011). World Health Organization/World Bank.
http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf

section 2

GUIDING PRINCIPLES OF DISABILITY-INCLUSIVE DEVELOPMENT IN EYE HEALTH PROGRAMS

Key messages

- ▶ Understand that awareness, participation, comprehensive accessibility and the twin-track approach (disability-specific actions and mainstream approaches) are core principles of a rights-based approach to disability-inclusive development.
- ▶ Engage with people with disability (for example, through DPOs) as key individuals who can bring expertise in disability inclusion, especially in identifying and responding to access barriers, training and dispelling false beliefs and myths that may exist about disability.
- ▶ Be aware that some DPOs are disability specific, so seek out umbrella organisations or a range of DPOs to ensure that a variety of perspectives are gathered.
- ▶ Ensure that the barriers facing women with disability are also identified as some DPOs may be represented by men with disability and may not share the different experiences faced by women or girls.
- ▶ Connect with Community-Based Rehabilitation (CBR) programs as a key strategy for achieving disability-inclusive development. When CBR programs do not exist in an area, aligned approaches that focus on access to life opportunities are a valuable framework for disability inclusion.²²

Overview

This section offers a set of guiding principles to assist eye health services to become more disability inclusive. Of greatest significance is the principle of human rights where society has a responsibility to work alongside people with disability to ensure these rights are realised. The following are the key principles in accordance with a human rights approach:

Awareness of disability and its implications is the crucial first step in eye health programs becoming inclusive.

Participation of people with disability in a genuine and empowering way is essential for initiating community change.

Comprehensive accessibility incorporates the physical, communication, policy and attitudinal barriers experienced by people with disability.

The twin-track approach explicitly identifies specific actions targeted for people with disability in conjunction with mainstream inclusion.

What is disability-inclusive development?

Disability-inclusive development encourages awareness of and active participation by people with disability. This development approach respects the diversity in the contribution made by people with disability and appreciates that disability is an everyday part of the human experience. Disability-inclusive development sets out to achieve equality of human rights as well as full participation in, and access to, all aspects of society.

What does disability inclusion in eye health mean?

Disability-inclusive eye health programs are designed to welcome and support all members of a community – whether they do or do not have a disability, and no matter what their disability may be. Programs that plan for disability inclusion will ensure barriers are identified and removed, and that disability-specific processes are in place. Inclusive programs also ensure that people with permanent vision loss have access to wider opportunities.

Disability-inclusive eye health programs respond to attitudinal, physical, communication and policy-related barriers. The following points illustrate what disability inclusion can look like in an eye health program:

- ▶ Staff with positive perceptions about people with disability and attitudes that are welcoming and inclusive.
- ▶ The presence of large contrasting signage for people with vision impairment.
- ▶ Good-quality wheelchair access.

- ▶ Access to sign language interpreters for people who are deaf.
- ▶ A disability policy and a committee to oversee its implementation.
- ▶ Financial support to ensure people in poverty with disability can access treatment.
- ▶ Printed materials that include clear, strong contrast pictures to illustrate key points and use plain language for people with disability with low-literacy skills.
- ▶ Staff trained in communication skills for people with a range of disabilities, including mental health conditions, vision impairment, acquired brain injury and intellectual disability.
- ▶ A disability inclusion committee made up of staff with awareness of access strategies for people with a wide range of disabilities, including knowledge of particular access requirements for women and girls with disability.
- ▶ A focal person responsible for gender-sensitive disability inclusion.
- ▶ Networks, linkages, referrals and access to a low-vision unit.

Photo and story: CBM, Niger

Educational opportunities – Djibril is 11 years old, lives in Niger with his family and attends a school for children who are blind. Before attending school, Djibril's experience of the world was confined to the family farm, where he felt his way around in the dark. His family had little hope for his future, especially living on a remote farm in drought conditions. Djibril's family joined a community survival yard program with a CBM partner where he and his father, Moussa, worked hard to establish their yard, which included a water well, fencing, plants and farming animals. They now have clean drinking water, produce much of their own food and earn enough money for other expenses. CBM also arranged for Djibril to attend a school for children who are blind. Djibril's world began to grow, as did his hope for something more. Djibril says, *"I enjoy going to school. The teaching is good... I'm reading and writing Braille. I'm very happy. It's not that difficult."* Djibril's experience highlights the importance of connecting children who are blind to a school where they can receive a quality education, develop aspirations for the future and realise their full potential.



"When I grow up I want to work with the government, and I will do my best to bring peace to Niger and help people who are poor."



.....
“This course is very important for people with a vision impairment. It gives them a purpose and shows them and the others around them that we are all capable of anything.”
.....

– Anil Solankil
.....

Photo and story: CBM, India

Independent skill development for people with a vision impairment – Anil Solankil is 22 years old and works as a technology teacher in Ahmedabad, India. He trains a small class of students diagnosed with a vision impairment how to repair mobile phones using a range of low-vision devices. The two-year course provides each student with skills to start a business and earn a living. This course is one of nine available through a local DPO, BPA (Blind Persons Association), which empowers people with a vision impairment through livelihood training. After Anil completed the same mobile phone training course more than three years ago, he was motivated to empower others with the skills he has. Anil is now using his income to support his family and fund his way through teacher training college. Anil's story highlights the importance of connecting people with a permanent eye condition with local disability organisations. For Anil, a referral to BPA has meant that he is empowered through his livelihood opportunity, is accessing further training and is a role model for other people who have a vision impairment.

Checklist: Guiding principles of disability-inclusive development in eye health programs

- ☐ Does the eye health program link with DPOs?
- ☐ Are people with disability seen as a resource and used as trainers, participants in planning committees and staff members within an eye health program?
- ☐ Are CBR services accessed to support disability-inclusive eye health programs?
- ☐ Is the CBR framework utilised as an approach for implementing disability-inclusive practices? (See Section 3)
- ☐ Are staff aware of the prevalence of disability, and the rights and capacity of people with disability?
- ☐ Are staff aware of and responsive to particular barriers and needs of women and girls with disability, and those of elderly people? (See Section 5)
- ☐ Does the program have child-safe and child protection approaches in place for children with disability? (See Section 4)
- ☐ Do people with disability actively participate in the eye health program?
- ☐ Have attitudinal, physical, communication and policy barriers been identified and removed?
- ☐ Are linkages made with community-based services to ensure people with disability have access to broader opportunities?
- ☐ Are there two-way referral processes between eye health programs and disability-focused programs?
- ☐ Do both disability-specific supports and mainstream services work together to generate a disability-inclusive program?

Useful resources and websites: Disability-inclusive principles

Community-Based Rehabilitation: CBR Guidelines. (2010). World Health Organization.
www.who.int/disabilities/cbr/guidelines/en/index.html

Convention on the Rights of Persons with Disabilities. (2006). Geneva: United Nations.
www.un.org/disabilities/convention/conventionfull.shtml

Facing up to disability. Shakespeare, T. *Community Eye Health Journal*. (2013). 26(81).
www.cehjournal.org/wp-content/uploads/facing-up-to-disability.pdf

How to make an eye clinic more accessible for people with low vision. Srivastava, J.
Community Eye Health Journal. (2012). 25(77), 13.
www.ncbi.nlm.nih.gov/pmc/articles/PMC3404441

Inclusion Made Easy: A quick program guide to disability in development. (2012). CBM.
www.cbm.org/inclusive-development

International Classification of Functioning, Disability and Health (ICF). (2001).
World Health Organization.

Low vision: we can all do more. *Community Eye Health Journal*. (2012). 25(77).
www.cehjournal.org/0953-6833/25/jceh_25_77.htm

Mainstreaming Disability in Development Cooperation.
www.make-development-inclusive.org

Inclusive Development Newsletter. CBM.
www.cbm.org/i/inclusive-development-newsletters-300575.php

section 3

DISABILITY-INCLUSIVE ACCESS FOR EYE HEALTH PROGRAMS

Key messages

- ▶ Comprehensive accessibility includes attitudinal, physical, communication and policy (including financial) access.
- ▶ Universal design respects the planning for products and environments to be useable by all people, to the greatest extent possible, without the need for adaptation or specialised design.^{2 3}
- ▶ Using ‘universal design’ principles in all building work is more cost effective when included at the point of design.
- ▶ People with disability commonly report social isolation, stigma and prejudice, often based on inaccurate assumptions about capacity and false beliefs about the cause of impairments.⁸
- ▶ In some cultures, people with disability may be unfairly seen as cursed, punished or carriers of bad fortune.⁸

Overview

This section identifies the most common access barriers to eye health programs for people with disability. The elements of comprehensive accessibility are highlighted here alongside practical solutions that can be adopted by an eye health program. It is important when addressing access barriers to consult with people with disability and Disabled Peoples Organisations (DPOs). Their input is valuable in ensuring innovative, low-cost strategies for creating inclusive eye health programs.

How to identify access barriers for people with disability

Access barriers include attitudinal, physical, communication and policy (including financial) barriers

Eye health programs include a broad range of services, such as vision screening, outreach, outpatient department services, counselling, medical and surgical treatment, and provision of assistive equipment such as spectacles or low-vision devices. People with disability will present at any of these services and may experience access barriers. It is important that these barriers are identified and addressed to create a welcoming and inclusive eye health program.

Universal design

Universal design principles are used in the built environment, education, communication and other areas where it is important to create a setting accessible and useable for all. Ensuring a universal design approach means that as many people as possible can access a program with minimal barriers.¹⁶ Through universal design principles, people with disability are consulted to determine their access needs alongside other community members and key stakeholders.

Using universal design, features such as access points, doorways and signage are designed with people with disability in mind. As a result, entrances have ramps, doorways are uncluttered and wide enough for people in wheelchairs and signs are at eye level, large with clear text and good colour contrast. This design approach is of benefit to all who access an eye health program.

Implementing universal design principles

Incorporating universal design principles into a health service is a useful process that benefits a wide variety of users, including people with disability. It is important to consider the implementation of universal design principles as a staged process; that way some actions can be built into current practice and other actions can occur over time. The following are some ideas for phasing in the principles of universal design:

Stage one

- ▶ Establish an inclusion committee representing the variety of groups who access the eye health service. Include women, men, DPO representatives, children, elderly people, staff and service personnel. Have the committee identify all access barriers including physical, communication, policy and attitudinal barriers. For example, an investigation of policy barriers could identify the need for financial support for people with disability.
- ▶ Identify urgent and low-budget access needs that the eye health program can respond to first. For example, ensure the entrance is accessible to all and corridors are kept clear of obstructions.

Stage two

- ▶ Use an inclusion committee to conduct a full audit of the building and identify aspects that can be adapted to meet universal design principles. This can include using ramps instead of steps, plain language/pictorial information, strong colour contrast, good lighting and large print signage.
- ▶ Review policies and practices to ensure the principles of universal design are reflected.
- ▶ Train staff on universal design principles.
- ▶ Identify a senior staff member to be a disability-inclusion officer responsible for all aspects of inclusion, such as universal design building access.

Stage three

- ▶ Adhere to universal design principles for all new building opportunities. For example, consider building separate male and female accessible toilets, which are important in ensuring people with a range of disabilities are able to attend the eye health service.
- ▶ Review all future building plans and ensure they adhere to universal design principles.



Photo: CBM, Kirivong Vision Centre, Cambodia

Universal building access – The design of the Kirivong Vision Centre in Cambodia has adhered to universal design principals with a ramp entrance. This is of benefit to many individuals who access the centre including elderly people, pregnant women, people with disability and delivery staff.

Community-Based Rehabilitation (CBR)

CBR is a rights-based participatory approach to disability inclusion and poverty reduction through rehabilitation, social inclusion and equity of opportunity. CBR aims to remove disabling barriers, address the causes of disability and bring people with and without disability together equally, with an overarching contribution to poverty reduction and improved quality of life for all.

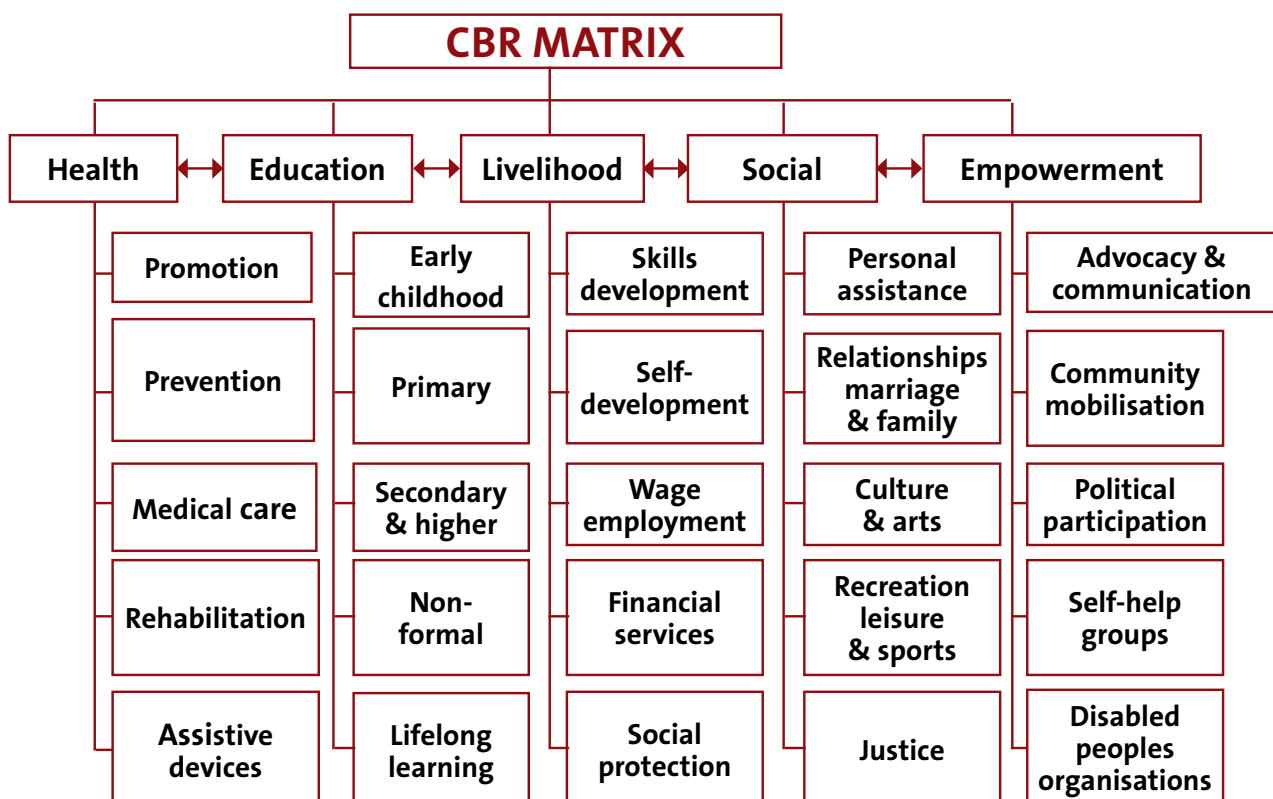
CBR enables targeted development for disability inclusion at the local level, reaching the poorest and most marginalised people with disability. Over the past 20 years CBR has matured from a mainly medical and rehabilitation focus to a comprehensive rights-based approach, targeting disability-inclusive community building and self-empowerment. The principles of awareness, participation, comprehensive accessibility and the twin-track approach are now common in many CBR initiatives. In particular, CBR embraces the twin tracks of individual disability-related interventions alongside inclusion and mainstreaming across the five domains of health, education, livelihood, social inclusion and empowerment.

CBR guidelines

CBR guidelines provide detailed information on Community-Based Rehabilitation. Each CBR program is specific to its local context and is dependent on the skills, available resources and capacity of CBR teams or individual workers. The intention is that all CBR programs operate within a network of organisations and entities in order to ensure a multi-sectoral, rights-based approach. Even in areas where CBR programs do not exist, the guidelines provide an important framework for disability-inclusive community development. CBR guidelines have been developed in collaboration with WHO, UNESCO and IDDC and can be found at www.who.int/disabilities/cbr/guidelines/en/index.html

The CBR matrix

The CBR matrix assists in identifying the diversity and depth possible within any given CBR program. Each of the five domains has been divided into elements that a CBR program may address.



Improving disability access in eye health programs

Identifying disability-related barriers and developing access solutions is a practical way to achieve disability inclusion. The following information identifies some common barriers to accessing health programs, along with practical strategies for inclusion of people with disability.

PHYSICAL BARRIERS	ACCESS STRATEGIES
People with disability may experience difficulties entering and moving around the eye health building.	<ul style="list-style-type: none">▶ Review physical access to the building, checking for ramps, hand rails, wide doorways and clear markings on the floor.▶ Ask people with disability through a local DPO to audit the accessibility of the building.▶ Ensure at least one obvious, signposted ramp entrance is available with a gradient, preferably 1:20, and never steeper than 1:12.▶ Ensure colour contrast at top edge of all steps and place high-contrast, raised markings (tactile indicators on the floor) at points of surface change.▶ Refer to national and local laws and policies that require disability access compliance for hospitals and other public buildings.
Rooms and other facilities such as toilets may not be accessible to people with physical disability.	<ul style="list-style-type: none">▶ Ensure each building includes separate accessible toilets for men and women, with wide entrances, door pull straps, 'grab' rails, and a low-level wash basin.▶ Ensure wide, unobstructed corridors and doorways throughout the building.▶ Make sure consultation rooms have enough space for a wheelchair to freely turn around.▶ Ensure equipment such as slit lamps allow full access for a wheelchair user.▶ Work with a DPO representing people with a physical disability and have a member check for physical access.

PHYSICAL BARRIERS

Health services may be in capital cities where people with disability from remote locations may find them hard to reach.

ACCESS STRATEGIES

- ▶ Create opportunities for mobile health facilities to remote communities.
- ▶ During mobile outreach, proactively seek out people from a diverse range of disability groups in need of eye consultations.
- ▶ Identify free or affordable accessible transportation to major eye clinics.
- ▶ Create opportunities through primary health care facilities or CBR programs.
- ▶ Ensure access to health services is financially affordable to the poorest people in a community, who often include people with disability.
- ▶ Network with existing services for referral processes.



Photos: CBM, Sierra Leone

Addressing transport barriers for people with disability – Mariama lives in Sierra Leone and has an amputated limb. She has been able to travel locally to a remote eye unit in order to access treatment for a severe eye infection. Access to local services, village screening and financial support for accessible transportation options go a long way to ensuring people with a range of disabilities have equitable access to eye health facilities in remote areas.

COMMUNICATION BARRIERS

People with a vision impairment may not be able to see all signs to locate and navigate around buildings.

Promotional information including community posters may not be accessible to people with specific learning disabilities, intellectual disabilities or a vision impairment.

ACCESS STRATEGIES

- ▶ Check the building to ensure that all signs are preferably between 1m and 1.5m from floor, of good colour contrast and in a large, clear print.
- ▶ Use clear images with good colour contrast on signs to ensure people with disability and others with low literacy skills are able to interpret information.
- ▶ Use tactile cues such as raised tiles or tactile indicators to assist people who are blind or vision impaired to orientate around the environment.

- ▶ Use large, clear print with good colour contrast to improve access for people with a vision impairment.
- ▶ Use pictures and plain language as many people with disability have had limited education opportunities and may not be able to read all information.
- ▶ Use other methods such as radio announcements and community meetings to inform people with disability about the eye health program.
- ▶ Raise awareness about the eye service with a range of community groups such as village health workers, CBR workers, DPOs and religious leaders.
- ▶ Raise information about the eye health program by sending accessible brochures home with patients to share with their community.

COMMUNICATION BARRIERS	ACCESS STRATEGIES
People who are deaf will have difficulty understanding spoken communication in meetings and consultations.	<ul style="list-style-type: none"> ▶ In consultation with people who are deaf or hearing impaired, determine the preferred forms of communication to be used. It is useful to present information in a range of modes such as in posters and print handouts. ▶ Identify local sign interpreters and possibly select a particular day each month where consultations are scheduled for people who are deaf.
Important information printed on medicine packets and brochures may be inaccessible to people who cannot access print.	<ul style="list-style-type: none"> ▶ Ensure vital information is provided in an alternative format such as large print or Braille for someone with a vision impairment. ▶ Clarify that spoken information such as that read from medicine packets is understood.

Photo and story: Groote Schuur Academic Hospital, Cape Town, South Africa

Improving access to eye health programs for people who are deaf – In the ophthalmology outpatients department at Groote Schuur Academic Hospital, a pilot program commenced in 2009 in which sign interpreters were offered to patients who were deaf or hard of hearing. This program was so successful that it now supplies a professional sign language interpreter on a designated day each month. One of the most important features of this program is the recognition that eye sight is extremely valuable for people who are deaf and dependent on sign language for communication. A strength of the program is its consultation and partnership with local DPOs. An added benefit has been the employment of people who are deaf. These staff not only contribute to the workforce but also bring specific knowledge of strategies to engage local deaf community members to come to the service for vision screening. This project has resulted in a monthly mobile phone text message promotion to a growing database of people who are deaf. In addition, on the day of the service, staff who are deaf meet and greet new clients and assist the interpreter throughout the visit. These staff stay with patients, explain the process of the appointment and ensure comprehension of technical information such as administration of eye drops. The presence and contribution of people who are deaf has dramatically improved awareness and acceptance of deafness in the eye health program.

ATTITUDINAL BARRIERS

Negative community attitudes and myths about disability – including for women, girls and elderly people with disability – may lead to a sense of reduced acceptance.

ACCESS STRATEGIES

- ▶ Address negative attitudes about disability, especially those based on false beliefs about how impairments are acquired.
- ▶ Engage with local DPOs to run staff disability awareness training to encourage positive perceptions.
- ▶ Employ men and women with disability to reinforce the valuable contributions people with disability can make to the workforce, ensuring relevant supports are in place.

“You know acceptance is happening when there is humour and interactions are warm.”



Photo: CBM, CTEH Cambodia

POLICY/FINANCIAL BARRIERS	ACCESS STRATEGIES
<p>Eye health program fees may be prohibitive for people with disability and their family members, especially when 22% of the world's poorest people have disability.</p>	<ul style="list-style-type: none"> ▶ Be mindful of how family money is allocated regarding people with disability accessing health care, especially for women and girls. ▶ Reduce or remove costs, including travel costs, for people with disability and other people in poverty accessing eye health services.
<p>People who present with a vision impairment may feel discouraged if there are no relevant services or supports to be referred to.</p>	<ul style="list-style-type: none"> ▶ Identify community supports for counselling. ▶ Ensure referrals are made to CBR, education and other relevant services. ▶ Ensure referrals are made to low-vision rehabilitation services, including prescription of low-vision devices. ▶ Connect people who are identified with a permanent eye condition with a local DPO and CBR program or relevant personnel where available. ▶ Reinforce capacity, potential and supports which mean that people with a vision impairment and other disabilities are viewed as valued members of their community.



Photos and story: CBM, CTEH Cambodia

Disability-inclusive eye health – Caritas Takeo Eye Hospital (CTEH) in Cambodia has taken proactive steps to strengthen its disability-inclusive practices over the past five years. This was initiated in 2008, when the old dilapidated eye hospital was replaced with a brand new facility. As a major donor, CBM encouraged the local partner, CARITAS Cambodia, to grasp the opportunity to include high-quality accessibility standards in the new building from the beginning. The hospital program staff appreciated that a ‘design for all’ approach – reducing the physical barriers for everybody, regardless of age and ability – would result in a win-win situation for all patients, not only those with disability. The new buildings have also been designed for maximum cross-flow ventilation in the tropical climate, making a pleasant environment for all patients, including those with disability. In addition, staff at the eye hospital acknowledge that it is crucial to share a clear understanding and definition of disability.

Recognition that people with disability were less likely to access the eye health program than those without disability prompted a change in practice and dramatically increased the number of cataract surgeries performed. The hospital now has an accessible building, staff trained in disability inclusion, a broad network of services for referrals (including CBR) and established education and training resources. It has also developed a computerised health information system with data collection on self-reported disabilities. In addition, the eye hospital successfully advocated for a disability-inclusion training module in the National Program for Eye Health of the Ministry of Health Cambodia, as part of the national primary eye care curriculum.

Checklist: Creating disability inclusion in eye health programs

- ☐ Have barriers to access to eye health programs been identified and potential solutions explored?
- ☐ Are people with disability and DPOs consulted to identify and respond to access barriers?
- ☐ Are outreach services conducted in disability-accessible locations?
- ☐ Are eye health programs promoted in a variety of formats to ensure people from all disability groups are able to access this information?
- ☐ Have facilities been reviewed for their accessibility, including provision of ramps, handrails, accessible toilets and appropriate signage?
- ☐ Are there fee structures and mechanisms that ensure people with disability who cannot afford the service are able to access and benefit from necessary eye health programs?
- ☐ Have specific actions been taken to ensure access by women, children and elderly people with disability?
- ☐ Are affordable glasses and low-vision devices available to all patients, including children?
- ☐ Is training provided in the use of low-vision and other assistive devices?
- ☐ Are transport options available, accessible and affordable for people with disability?
- ☐ Do eye health programs exist in partnership with community organisations, including DPOs and CBR?

Useful resources and websites: Creating disability-inclusive eye health programs

Accessibility Design Guide: Universal design principles for Australia's aid program. AusAID.

www.ausaid.gov.au/publications/Pages/accessibility-design-guide.aspx

Medical Eye Care Policy. (2010–2012). CBM.

www.cbm.org/article/downloads/54741/Medical_Eye_Care_Policy.pdf

Inclusive Development Newsletter. CBM.

www.cbm.org/i/inclusive-development-newsletters-300575.php

Community-Based Rehabilitation: CBR Guidelines. (2010). World Health Organization.

www.who.int/disabilities/cbr/guidelines/en/index

Community Eye Health Journal.

www.cehjournal.org

Mainstreaming Disability and Gender in Development Cooperation. International Disability and Development Consortium.

www.make-development-inclusive.org/toolsen/03_mainstreaming.pdf

Promoting Access to the Built Environment Guidelines. CBM.

www.cbm.org/article/downloads/54741/CBM_Accessibility_Manual.pdf

Removing barriers to health care: A guide for health professionals. Mace, R. (1998). North Carolina: The Center for Universal Design.

<http://design-dev.ncsu.edu/openjournal/index.php/redlab/article/viewFile/91/45>

section 4

APPLYING DISABILITY-INCLUSIVE PRACTICES IN EYE HEALTH PROGRAMS

Key messages

- ▶ Eye health promotion following principles of disability inclusion will enable all community members to access information on health promotion, vision screening and blindness prevention.
- ▶ Eye health programs should be aware of approaches to locate, attract and identify women, men, girls and boys with disability.
- ▶ Screening and patient transfer and transport processes should be aware of and cater for people from a diverse range of disability groups.
- ▶ Outreach services should be advertised using a range of formats and networks such as large print, pictorial, radio announcements and community meetings.
- ▶ Individual information and counselling should be offered to people with disability.
- ▶ People with a newly acquired vision impairment should be referred to services that will foster independence such as CBR, a low-vision clinic, inclusive education and a DPO.
- ▶ Reliable follow-up services are essential to ensure all individuals with a disability are monitored for ongoing or additional medical care needs.
- ▶ Follow-up is essential with individuals who may have already been to an eye hospital to see if their eye condition has changed or whether other services are required.

Overview

- ▶ The management of eye health programs varies in different places along with the governments, organisations, health systems and cultures they operate in. Recommendations in this section are not exhaustive and are based on commonly occurring processes in eye health programs. The recommendations support personnel who can influence and strengthen policy and procedures. Individual services are encouraged to adapt suggested strategies to their context. Remember that change can take time, so it is important to persevere.

Photo and story: Fred Hollows Foundation, Cambodia

Returning to work following eye surgery – Mr Hen Vin is 68 years of age and works as a farmer in Cambodia. He lost his leg in a mine explosion during the Pol Pot regime. When he then experienced vision loss through cataract, he was unable to work or support his family. Hen Vin connected with one of the Fred Hollows Foundation's outreach services close to his home and was able to receive treatment that has been life-changing for him and his family. After being screened in his village by the Fred Hollows Foundation partner, he travelled 40km to Oddor Meanchey Eye Unit to have surgery for his bilateral cataracts. With Hen Vin's existing disability, it was even more significant for him to have his sight restored.



National blindness prevention plans

Most countries will have a blindness prevention plan. It is important that those responsible for monitoring this plan recognise the importance of disability inclusion so as to reflect all community members. The following points outline key ideas to ensure disability representation in your country's blindness prevention plan.

- ▶ Nominate a representative with a disability from a DPO for membership on the monitoring committee.

- ▶ Ensure staff responsible for implementation are aware of disability prevalence and gender-sensitive disability inclusion in all eye health programs.
- ▶ Work with government to ensure awareness of disability-inclusive eye health programs and partner with other relevant government bodies.
- ▶ Promote strategies in this guide for disability inclusion in all phases of eye health programs.

Health management information systems

Collection of appropriate health information is an important part of all quality health programs. Health information systems provide vital opportunities to learn more about patients and use the information to better inform future services. Attaining basic information about disability types and prevalence is important. In addition, it is critical to identify gender and age specific barriers or imbalances in seeking and accessing health services.

Efficiently identifying people with disability in busy eye health departments is an ongoing challenge. Questions often used to identify the presence of disability and type of impairment vary widely and, as a consequence, so do the results. Self-identification is a common approach to recording the presence of disability, but this generally leads to lower levels of identification as it depends on a person's knowledge and confidence in disclosing their disability. Reluctance in disclosure or self-identification with a disability can relate to negative community attitudes and stigma connected with the potential of myths about disability.

Locating people with disability

It is important to seek out people with disability for inclusion in all eye health programs. This is necessary both to reflect the community as well as to gain the valuable dimension and input that people with disability have to offer in the planning and delivery of eye health programs. Importantly, the language of 'disability' may not always be appropriate due to stigma and local understanding of this term. It is therefore critical to work with DPOs to identify the most suitable language to use when seeking out people with disability. The following information offers guidance in using existing data sources, disaggregating data and using local networks for finding people with disability for inclusion in eye health programs.

Pre-existing data sources

The following list outlines key population-based data sources for identification of people with disability. Note that such data sources frequently underestimate the prevalence of disability due to poor country identification and reluctance to self-identify.

- ▶ Census-based data.
- ▶ Data from community health programs, hospitals, CBR and disability services.
- ▶ Education data including data from the Ministry of Education, mainstream schools, inclusive education resource facilities and special schools.
- ▶ Government ministries for social affairs, disability and health.
- ▶ DPO umbrella organisations and local DPOs. (Note that some DPOs will be disability specific so it is worth meeting with more than one DPO where possible.)
- ▶ Global documents on disability such as the *World Report on Disability*.

Community approaches for locating people with disability

- ▶ Use a key informant method or a 'snowball' technique to identify people with disability in the program target area. This can be done by asking people to refer you to homes and areas where people with disability may live.
- ▶ Work with DPOs.
- ▶ Determine local language for 'disability' and understand other words, phrases and symbols that may be used to represent disability. Some languages will only use 'disability' to refer to a physical impairment and have other terms for sensory impairments and other disability types.
- ▶ Recognise different terms to identify an acquired disability in contrast to being born with a disability. These terms need to be understood since one term may, for example, be carried with pride and another with shame.
- ▶ Connect with religious and traditional leaders and healers who may be aware of people with disability in their communities.



Photo and story: CBM, Kenya

Accessing community-based disability

services – Amina has a hearing impairment and was severely impacted by her reduced vision, especially as she relied on her sight to support her lip reading. Following surgery for congenital cataracts, she received glasses to further correct her vision. She is now also receiving rehabilitation activities for her severe hearing impairment. Amina's story illustrates the importance of eye health programs having strong awareness of disability services in the community and referral systems in place.

Washington City Group disability statistics

The Washington City Group set of disability questions has been established for collecting census data globally and is recommended to support the identification of impairment and disability prevalence. These questions reflect social models of understanding disability by asking questions related to 'functioning' and have been found to detect higher levels of disability in the community. The following questions from the Washington City Group can be used to support identification of functional limitations.

Have you had difficulty for the last six months, with any of the following?

- ▶ Difficulty seeing, even if wearing glasses
- ▶ Difficulty hearing, even if using a hearing aid
- ▶ Difficulty walking or climbing steps
- ▶ Difficulty remembering or concentrating
- ▶ Difficulty with self-care (such as washing all over or dressing)
- ▶ Difficulty with communicating or being understood

To find out more about the Washington City Group questions, go to: www.cdc.gov/nchs/data/washington_group/WG_Short_Measure_on_Disability.pdf

Disability disaggregated data

In addition to the Washington City Group questions, information can be asked of community members to determine disability. When collecting data, ask about the type of disability and how daily functioning is likely to be impacted and managed. If disability-related information is not already sourced in your eye health program, consider selecting relevant questions from the following list:

- ▶ Do you have an impairment that affects your daily functioning?
- ▶ Do you support a family member with a disability?
- ▶ Do you have a physical impairment that impacts your daily movement?
- ▶ Do you have poor eyesight that impacts your ability to see for reading and mobility?
- ▶ Do you have poor hearing or communication difficulties that impact your ability to participate in conversations?
- ▶ Do you have a chronic medical condition that impacts your daily activity?
- ▶ Do you have a mental health condition or psycho-social impairment that makes daily functioning difficult?
- ▶ Do you have difficulties thinking and reasoning that make it hard to live independently?

Recommendations for disability inclusion in data-gathering systems

- ▶ Collect information on disability type, age and gender.
- ▶ Adopt the Washington City Group set of questions to support collection of data, especially when people are unable to name their health condition or identify with a disability label, yet present with functional limitations.
- ▶ Align data collection with Ministry of Health disability data where relevant, so that information can be integrated into national health information systems.
- ▶ Record all referrals to disability services such as CBR and DPOs.

Screening and initial identification opportunities

Screening activities are often the first point of contact a person with disability, including a vision impairment, has with an eye health program. It is important to note that there are still many people with disability not included in screening due to lack of knowledge, inaccessible facilities or (at times) discriminatory attitudes of the community and staff. It is crucial that people with disability are treated respectfully, and where appropriate, identified for specific follow-up. Tests used in vision screening need to be accessible and understood by all people with disability.

Disability-inclusive screening

- ▶ Promote screening activities to communities through CBR and DPOs, ensuring accessibility for people with disability, especially women and girls.
- ▶ Provide information in multiple formats such as large print, pictures, plain language, radio promotion, house-to-house communication and community sessions (for example, through religious groups and community meetings).
- ▶ Hold screening activities in convenient, accessible and affordable locations. If waiting times are long, provide a separate queue for children and adults with disability, other vulnerable groups such as elderly people, and nursing mothers. Offer seating, shade, drinking water and shorter waiting times.
- ▶ If screening is occurring in schools for local children, work with teachers to identify characteristics of children who may have a vision impairment.
- ▶ Be aware that approximately one in three children who are not in school have a disability. It is therefore important to work with community groups to locate all children to ensure they access school or other vision-screening services.
- ▶ Work with Village Health Workers and Primary Health Care staff to identify people with disability who may show symptoms of reduced vision.
- ▶ Ensure health programs have strong networks with local disability services.
- ▶ Train CBR workers to be involved in vision screening and eye health programs.

Disability-inclusive patient transport and transfer options

Patient transfer options and transport to health services is a common barrier experienced by people with disability. Transport is often limited, expensive and unreliable. Costs can also be unpredictable and prohibitive for people with disability. It is therefore important to ensure that transport and transfer options respond to the particular needs of people with disability.

Recommendations for disability-inclusive transfer and referral processes

Prohibitive costs and fear of the unknown are significant factors that may prevent people from following up on referrals. It is essential that all patients receive comprehensive information about the eye program at the time of referral. This should outline all costs and details involved for the patient and any accompanying person, such as accommodation, feeding and bathing arrangements, transport options, clinic days and hours, location and likely length of stay. If cost is a barrier, the eye health program should have systems in place to support

people with disability in accessing services. The following are some suggested recommendations to support disability-inclusive transfer processes:

- ▶ For all people with disability (including those with vision impairment) who have been referred to an eye health program, determine additional disability support requirements in relation to rehabilitation, accessible travel arrangements and financial assistance.
- ▶ Ensure provision of accessible referral and transfer information.
- ▶ A 'transfer pathway' including transport and other services should be made accessible as this is a vital part of a disability-inclusive service, giving patients the confidence to act on their referral.
- ▶ All elements of transfer pathways need to be clearly explained and their timing and costs made clear to patients and their families.
- ▶ Provide specific information to individuals with a mental health condition, autism, acquired brain injury or intellectual disability who may be unsure about transfer processes.
- ▶ Allow for transport support for a carer or sighted guide if a companion is required for a patient with a disability.

Individualised delivery of information and counselling

Receiving a diagnosis of a permanent vision impairment or blindness is a significant event in anyone's life. For people with disability, the process of diagnosis and subsequent information provision and counselling should occur in an inclusive and quality patient-focused manner. Human and time resources can be a serious constraint for many services, yet even a very short checklist for providing information for affected patients can make a substantial difference in their adjustment to vision loss and 'whole of life' outcomes.

Recommendations for individualised information and counselling

- ▶ Develop a protocol for the process of diagnosis of blindness or low vision, including patient management. Ensure it is clearly documented and understood by relevant staff. Good processes will prevent inconsistent care being provided.
- ▶ Train nurses and other staff on the critical importance of counselling and information provision. Many individuals and parents of children with blindness may feel 'hopelessness' and 'failure' when first diagnosed. It is essential that information is delivered in a reassuring, sensitive and timely manner.

- ▶ Promote inclusion in mainstream schools and referrals to support services. It is important to recognise that children with a vision impairment or blindness can be well supported in their local school. Promote successful inclusive education examples of students with a vision impairment in your region.
- ▶ Ensure that counselling staff are aware of particular vulnerabilities for girls and boys diagnosed with a vision impairment, who are at an increased risk of sexual abuse and are more likely to be excluded or withdrawn from education. It is important that this is addressed during the counselling stage and that disability-inclusive education is promoted.

“Simply training staff to say, ‘There is nothing more I can do for you; however, I am referring you to person A who will provide you with important and helpful information’ versus saying, ‘Nothing can be done for you’ can make an enormous difference to the psychological well-being and ‘quality of life’ for people with permanent vision impairment.”²⁶

Referral to a disability service or DPO

Once a diagnosis of a vision impairment has been made and appropriate information and counselling has been offered, the next step is for a referral to a service focused on disability management and support strategies. A consistent process for referrals should be embedded into all eye health services, with sound awareness of relevant disability organisations within the community.

Recommendations for referral to disability services and DPOs

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

- Identify the need for referrals to support people with other disabilities such as a hearing impairment. Some individuals with a disability may present for vision screening and may have never connected with any other disability services.

Photo and story: Royal Australasian College of Surgeons, Timor Leste

Referrals to disability services –

The Royal Australasian College of Surgeons (RACS) has worked closely with local NGOs in Timor Leste to deliver Braille and vocational skills training, as well as supporting vision-rehabilitation NGOs in expanding their activities. Approximately 47,000 Timorese over the age of 40 are vision impaired, with cataract and refractive error responsible for up to 90% of all cases (NEHS, 2006–2011). Culturally appropriate rehabilitation services are paramount to the country's socio-economic development. In response, under the Avoidable Blindness Initiative, RACS has worked with local and international implementing partners (Fred Hollows Foundation New Zealand; East Timor Eye Program; the National Eye Centre [NEC] in Dili; Guide Dogs Queensland; Fuan Nabilan; and East Timor Blind Union [ETBU]) to improve access to vision support services for individuals who cannot be assisted by eye surgery. The vision-rehabilitation component of the program focuses on improving referral strategies to ensure people are directed to appropriate services across Timor Leste. At screening sessions, eye care personnel have copies of the *Community-Based Rehabilitation in Timor Leste Directory*, developed and published by the Ministry of Social Services.

Programs promoted include Braille training; capacity building of public primary school teachers to include children with permanent vision loss in their regular classrooms; vocational training to teach production of handicraft and household items; and massage training. With over 40% of the population of Timor Leste living on US\$0.55 per day, access to training in education and livelihood skills results in significant confidence building and opportunities for people with disability in Timor Leste.



Checklist: Development of vision-impairment management skills

When working with people who have been diagnosed with a permanent eye condition, it is important to ensure confidence in the independent management of their disability. This is especially relevant when the individual already has another existing impairment. The following is a checklist identifying some management skills for people diagnosed with a permanent eye condition:

- ☐ Ensure the individual is informed of the name and description of their eye condition and understands its potential impact and progression.
- ☐ Ensure access to counselling services to support them in adjusting to the vision loss.
- ☐ Ensure provision of low-vision devices and training in their use.
- ☐ Provide access to sighted guide training for family/community members to promote confident and safe guiding around home and community.
- ☐ Ensure access to an appropriate mobility device such as a long cane if needed.
- ☐ Ensure orientation and mobility training for independent mobility skills.
- ☐ Provide training in activities for daily living, including reading and writing, cooking, cleaning, mobility and self-advocacy.
- ☐ Encourage and support the process in a return to school or work.
- ☐ Retrain for reintegration into work or for alternative livelihood skills.
- ☐ Make connections with CBR, DPOs, education, training and mainstream inclusion options, including social inclusion, empowerment, education and engagement in livelihood activities.
- ☐ Foster connections between DPOs and individuals with a vision impairment to support them in developing community connections with people skilled in management of their disability.
- ☐ Be aware of and source training in the use of relevant adaptive devices designed to support social inclusion of people with a vision impairment.
- ☐ Create opportunities to provide feedback to the eye health program and to disability services to improve the effectiveness of response to people with permanent eye conditions.

When disability services do not exist locally

If diagnosis of low vision or blindness occurs but there is no locally available disability service, then ideally the eye health program can make provision for this – for example, prescribing low-vision devices, basic mobility training and promotion of ‘activities for daily living’. To support this process, ensure family members are also present.

Disability service organisations should be contacted for advice on other ‘centre-based’ services that the family or individual may be able to access, including referrals for educational and vocational guidance if needed.

Follow-up services

Reliable follow-up services are an important part of any quality eye health program. A disability-inclusive eye health program will ensure patients with disability are provided with additional information and support relevant to their treatment plan. It is also important to consider any follow-up support for patients diagnosed with a permanent eye condition who require monitoring or additional treatment.

Recommendations for follow up services

- ▶ Include perspectives and needs of people with disability and their families.
- ▶ Ensure consistent processes for patients to understand why, what and when follow-up is required. This should include provision of time frames when there is more than one check-up within a year.
- ▶ Provide follow-up information in an accessible format. In addition, clarify to ensure the individual understands the process. Include provision of information to a carer if required (for example, for someone with an intellectual disability).
- ▶ Ensure provision is made for accessible and affordable transport to a referral service.

Community eye health promotion

Health promotion activities are an important part of all eye health programs as they educate community members about the causes of vision loss and focus on prevention of blindness. Health promotion activities can also integrate positive messages about people living with disability (including vision impairment and blindness) and their important contributions to education, livelihood and community groups.

It is important to present eye health information in a range of formats including large print, posters, pictorial format, Braille, plain language, audio (including radio announcements) and community meetings. This will ensure all community members – including those with vision impairments, hearing impairments, acquired brain injury and intellectual disabilities – will have access to this information.

Recommendations for eye health promotion

- ▶ Consult with people with disability and DPOs to identify preferred formats. Accessible formats will benefit the whole community, including people with low literacy skills able to receive audio and pictorial eye health information.
- ▶ Work with DPOs in disseminating eye health promotional messages to ensure information is given to all community members with disability.
- ▶ Deliver accessible eye health promotion information to community groups such as schools, religious leaders, health and CBR workers. Send accessible brochures on eye health services home with patients to be shared with other community members.
- ▶ Include positive messages and images about the inclusion and capacity of people with disability in eye health promotion activities.
- ▶ Be aware of people with disability who are older and ensure eye health messages are available to these important community members.
- ▶ Use people with disability to support delivery of eye health promotion messages, especially when promoting disability inclusion.
- ▶ Engage with women and children with disability and build their capacity to share eye health promotion messages among their communities.

Children with disability

It is crucial to recognise the presence and impact of disability on young people. One in twenty children globally have a disability,²⁷ and 80% of children with disability under five years of age live in developing countries.²⁸ Importantly, the vulnerability of children needs to be recognised, with children with disability being at a much higher risk of violence and other abuse than those without a disability.²⁹ Two hundred million children under five years of age, globally, do not reach their cognitive and social-emotional development potential.³⁰

Children diagnosed with blindness or vision impairment

It is important to work with children and their parents/caregivers when a diagnosis is made. A focus on fostering the empowerment of children and connection with education providers, disability services and a DPO is critical in ensuring children with a newly identified vision impairment remain connected with their community and skilled in strategies to manage in activities for daily living. It is especially important for children diagnosed with a vision impairment to be linked into their local school. This supports broader community inclusion and awareness about the capacity of people with disability. Teachers and family members should be trained in disability-inclusion techniques (such as mobility training) to foster independent living skills. In addition, early intervention activities (medical, rehabilitation, social and educational) for children with vision impairment are essential in order to support improved quality of life, both during childhood years and as adults.



Photo and story: Fred Hollows Foundation, China

Childhood access to eye health services – Kang Yiwei is a six-year-old boy living in China. He has amblyopia, also known as lazy eye, resulting in reduced ability to see out of one eye. If untreated in childhood, this can result in a permanent vision impairment. Kang Yiwei was treated at the ophthalmic centre in Jiangxi. Access to this eye health program demonstrates the importance of placing eye care services close to communities. This results in increased access for people from all disability groups, including those with a vision impairment.

Child protection policy in eye health programs

It is essential to have a child protection policy that includes protection of children with disability in all eye health programs. Here are some ideas to raise awareness of the policy among eye health program staff:

- ▶ Ensure the policy is read and understood by all staff.
- ▶ Ensure staff are aware of the particular vulnerability of children with disability.
- ▶ Ensure staff sign a child protection code of conduct.
- ▶ Adhere to mandatory reporting requirements and other local legal obligations.
- ▶ Establish a child protection working group to develop and monitor the policy.

Rose's story

Rose was born in rural West Africa and became totally blind at the age of one due to measles and vitamin A deficiency. As she grew she learnt to move around the village and do many household jobs, but she did not attend the local school with her peers. An eye care outreach team who visited the village encouraged Rose's mother on several occasions to take her to a boarding school for children with a vision impairment in the capital city. Rose's mother was reluctant due to cost and Rose's safety; however, after much encouragement and financial support from school staff, Rose's family took her to board at the school in her early teens. Rose's family then noticed that she was not happy at the school, and halfway through her second year, a message came to the parents that Rose had been very naughty and was pregnant, and that they needed to collect her immediately. On reaching the capital, Rose's mother did all she could to find out what had happened. It became clear that the father was a long-standing staff member at the school. Rose's family attempted to seek justice but ended up returning home with Rose, who delivered the baby safely several months later.

Rose's story is a valuable reminder that all schools, especially with boarding facilities, should be child safe and have very strong protection policies in place. Also, families, in partnership with professionals, should feel empowered and have access to a range of education options for a child with disability.

A consultation on disability-inclusive eye health programs

In India in 2012, CBM's Medical Eye Care Advisory Working Group met with disability practitioners, including people with vision impairment, to discuss strengthening and embedding disability inclusion in eye health programs. The group agreed that disability inclusion in eye health should ensure access, best quality outcomes and improved quality of life for all eye patients and people with vision impairment. The group discussed strategies to remove access barriers, the specific measures required to include women and children, and services relevant for people diagnosed with a permanent, untreatable eye condition. This, along with other consultations, led to a series of recommended actions for improving disability inclusion in eye health programs, many of which have been built into CBM's Medical Eye Care Policy. Key actions resulting from the consultation include:

- ▶ Consult with local DPOs in planning.
- ▶ Employ people with disability to work in eye units.
- ▶ Appoint a member of staff as the coordinator for disability inclusion in all eye units (e.g. through a part-time role or time allocation for an existing staff member).
- ▶ Identify barriers to access, both internal and external, noting easy and difficult-to-fix options. Put in place an action plan to address these barriers.
- ▶ Consider any specific 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 rehabilitative services.
- ▶ Ensure counselling, linkages and referral to rehabilitation and education services for people with untreatable eye conditions that result in permanent vision loss.
- ▶ Ensure physical accessibility and large contrasting signage in eye units.
- ▶ Specifically plan for the provision of services for people with a hearing impairment.
- ▶ Provide disability inclusion training for eye unit staff, raise awareness with other stake-holders and follow up with refresher training.
- ▶ Use a strengths-based approach, acknowledging and building on capacity and existing high quality initiatives.
- ▶ Staff with heaviest loads (such as ophthalmologists) should be encouraged to refer patients with permanent vision loss to other skilled staff in the unit.



Photo: CBM, Niger

Disability inclusion co-ordinators in eye units – In its meeting on disability-inclusive eye health programs, CBM’s Medical Eye Care Advisory Working Group recommended that a staff member be appointed as ‘co-ordinator for disability inclusion’ in all eye units. This may be a part-time role. The disability inclusion co-ordinator can provide training to other personnel and promote very positive messages to patients, their families and communities. These messages include promoting access for people with all types of disabilities and for women and children, to eye clinics and camps, even in remote regions. They also include positive messages that people with long-term vision impairment be given wider opportunities in low-vision services, education, rehabilitation, mobility, living skills, livelihood and their social lives.

- ▶ Referral/transfer pathways in all directions to be well established and maintained.
- ▶ Create mechanisms to ensure poor people receive treatment as a priority, including financial supports.
- ▶ Advocate for disability inclusion modules to be built into all medical/nursing/allied health/primary health/health promotion courses.
- ▶ Encourage access to surgery even for patients where only slight improvement is expected. Minimal increase in vision functioning can provide a significant improvement in quality of life.

Disability inclusion in emergency eye health responses

People with disability are among the most vulnerable in all phases of an emergency. Due to the higher rates of poverty associated with disability, there are limited resources to foster resilience before, during and after conflicts or natural disasters. It is therefore essential that emergency medical programs, including those providing eye-care, take proactive steps to be disability inclusive. This is in line with both the SPHERE Humanitarian Standards³¹ and the CRPD.³² The following factors reinforce the importance of disability inclusion in eye health programs during an emergency:

- ▶ Disasters increase the vulnerability of people with disability due to separation from family, difficulty reaching safety, loss of mobility or other devices, loss of essential medications, and inaccessible warnings and information.
- ▶ In humanitarian responses, people with disability can be ‘invisible’ to relief workers and therefore fail to access essential supports such as medical care, food distribution, shelter, WASH (water, sanitation and hygiene) facilities, and family re-unification programs.
- ▶ The prevalence of disability (including vision impairment) increases during and after emergencies due to injury, infection and poor access to medical and other services.
- ▶ Disaster Risk Reduction (DRR) processes, trainings and warnings may fail to include people with disability.
- ▶ Women, children and elderly people with disability may be particularly vulnerable.

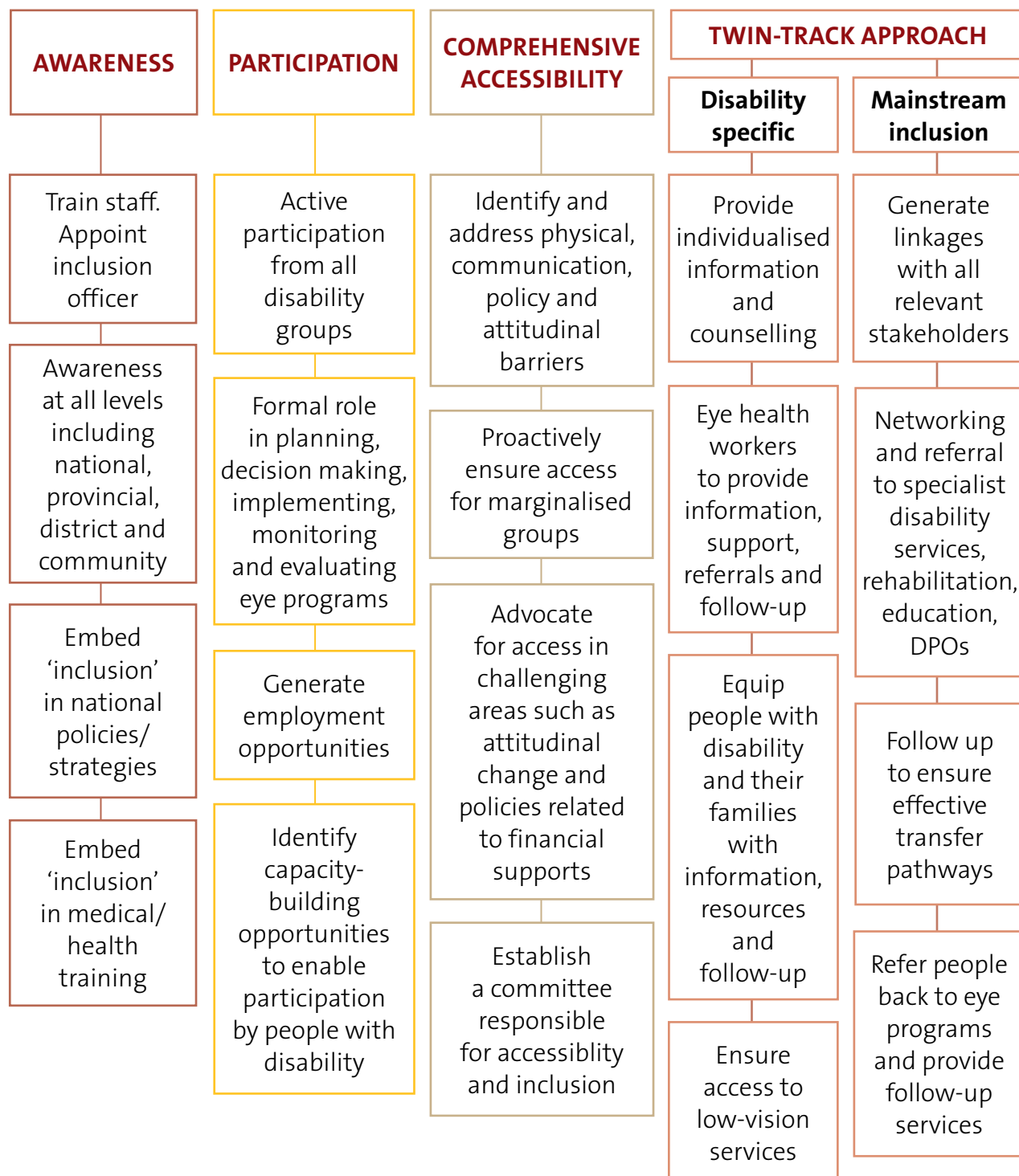


Photo: CBM, Democratic Republic of Congo Disability-inclusive emergency response – People with disability may face significant barriers in accessing emergency eye clinics. Good planning and proactive steps will support access to relevant treatment and referrals to additional available services.

Checklist: Disability inclusion in preparedness and action plans for emergency eye health programs

- ☐ Are there disability focal staff in the emergency medical team to ensure the rights and needs of people with disability are understood and met?
- ☐ Are people with disability involved in disaster preparedness planning, and have emergency staff worked with DPOs to anticipate access barriers (including environmental, financial, security, communication and transport barriers)?
- ☐ Have clear plans, activities and trainings been developed to address access barriers by people from all disability groups, including people with psycho-social conditions and intellectual disability?
- ☐ Has the program taken steps to address the extra needs that women, girls and elderly people with disability may face?
- ☐ Have linkages been created with CBR programs, DPOs, NGOs and government services to assist in preparedness and during the emergency?
- ☐ Is information about eye health clinics advertised in a variety of formats, such as posters, radio and word-of-mouth through districts and camps?
- ☐ Is there collaboration with other services to register people with disability for eye health, including locating people in obscure settings?
- ☐ At the clinic, has a separate queue for people with disability and other vulnerable groups been established, providing shade and drinking water?
- ☐ Are policies, protocols and trainings in place to ensure protection of people with disability, including women and children, ensuring a safe environment within the emergency camp and in the clinic area?
- ☐ In camps, are shelters for people with disability and their families in an accessible, secure location, close to water points, sanitation, lighting, health posts, and food and non-food item distribution points, if agreed to?
- ☐ Is the location of the emergency health clinic and its building/shelter accessible and secure?
- ☐ Does the program have systems to ensure fast replacement of essential devices such as glasses, mobility aids and eye care medications?
- ☐ Are people with disability supported in access to follow-up treatment, referrals to secondary/tertiary level eye care and rehabilitation?
- ☐ Is the program collaborating with other services to ensure quality of life for people with disability, including reunification with family, nutrition, Vitamin A distribution, immunisation, WASH facilities, humanitarian protection, child-safe areas and education in emergency programs?

Outline of disability inclusion in eye health programs



Foundational Principle: Building on Equity of Human Rights.

Each person has the right to protection, health (broad-based), education, livelihood, social inclusion and empowerment.



Photo and story: CBM, Cambodia

Recognising capacity in people with disability – Mao has been blind from the age of ten and states that “living life with blindness in any country is difficult, but when you’re living in Cambodia, you have to work hard to survive”. Mao missed out on an education due to his blindness. During the Pol Pot regime in the 1970s he recalls, “I had a lot of trouble during this time. Everyone would work during the day and at night they would study under candlelight. But I couldn’t. They treated me badly and forced me to work even though they knew I couldn’t see. They did not care. I was very upset and cried many nights.” With permanent blindness, Mao’s focus was on developing livelihood skills and earning enough money for his family. A CBM partner in Cambodia, CDMD, provided Mao with three small business loans. The first he used to buy some cows, the second to buy pigs and the third to plant rice. Each venture has been profitable as Mao and his family look ahead to beginning a more sustainable business. “Now that I can make a living I feel wonderful. My cows are fat and I’m thinking of making wine out of coconuts. I even climb the trees!” he says excitedly. From the money that he is making, Mao is repaying his loans and sending his two children to school. He has also bought a motorbike, which his son uses to help him run errands and purchase goods from the market.

“I used to find it hard to make money. I would hurt myself, get lost and get cheated when I sold things. But now I have hope and happiness; I have new skills that have provided me with enough for my family; I have goals and dreams.”

Checklist: Disability-inclusive practices in eye health programs

- ☐ Are eye-health staff, including those in management, aware of good practice for disability inclusion?
- ☐ Have service processes and protocols been developed, documented and reviewed to include disability?
- ☐ Are there specific opportunities to involve people with disability in decision-making in how the eye health program functions?
- ☐ Is data on disability being collected, together with that on age and gender?
- ☐ Does disability data include information on referrals to or from other services?
- ☐ Is there a budget line for disability inclusion?
- ☐ Does the eye health program have a disability focal person and inclusion working group?
- ☐ Does the eye health program have a child protection working group that is informed about the rights of children with disability?
- ☐ Are staff aware of the particular needs of women and girls with disability and their specific barriers in accessing eye health services?
- ☐ Does the eye health program have strong relationships with services and organisations working in disability, particularly CBR services, education programs and DPOs?
- ☐ Are staff aware of the role disability organisations can play, including their capacity to build disability management skills and facilitate empowerment of people with disability in community participation?
- ☐ Is there counselling available and referrals to relevant services following a diagnosis of a permanent eye condition?
- ☐ Does the eye health program have access to rehabilitation services and low-vision devices such as magnifiers and long canes, with relevant training?
- ☐ Do eye health promotion activities contain positive messages regarding the inclusion of people with disability?
- ☐ Is eye health promotion accessible for people with different disabilities?

Useful resources and websites: Disability-inclusive practices in eye health programs

The visually impaired child. *Community Eye Health Journal*. (2003). 16(45).
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Low vision care: the need to maximise visual potential. *Community Eye Health Journal*. (2004). 17(49). www.cejournal.org/0953-6833/17/jceh_17_49.html

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www.cejournal.org/0953-6833/20/jceh_20_62.html

Eye care for older people. *Community Eye Health Journal*. (2008). 21(66).
www.cejournal.org/0953-6833/21/jceh_21_66.html

Progress for Children: A report card on child protection. Number 8. (2009).
New York: UNICEF, 12.
[www.unicef.org/protection/files/Progress_for_Children-No.8_EN_081309\(1\).pdf](http://www.unicef.org/protection/files/Progress_for_Children-No.8_EN_081309(1).pdf)

Inclusive Development Newsletter. CBM.
www.cbm.org/i/inclusive-development-newsletters-300575.php

Inclusion Made Easy: A quick program guide to disability in development. (2012). CBM.
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Make Development Inclusive: How to include the perspectives of persons with disabilities in the project cycle management guidelines of the EC. (2008).
CBM International.

section 5

DISABILITY INCLUSION IN THE PROJECT CYCLE

Key messages

- ▶ The program cycle, with its focus on planning, implementation, monitoring and evaluation, provides a number of excellent opportunities and entry points for disability inclusion in the management of eye health and other programs and services.
- ▶ Including people with disability in eye health program decision-making processes and in evaluation teams is important for achieving disability inclusion.
- ▶ Understand how disability impacts your program and other services to assist in effective planning.
- ▶ Recognise the potential of people with disability in their active contribution to programs at all stages.
- ▶ Gather the variations in experiences of people living with disability from your patients and within the community, paying particular attention to how women and men and people of different ages may experience their disability differently.
- ▶ Ensure a child protection policy is in place that includes specific needs of children with a disability.
- ▶ If a disability, gender and age perspective is omitted during initial and updated planning, people with disability can be unintentionally excluded.
- ▶ It is smarter, easier, cheaper and more effective to be disability- and gender-inclusive from the start.
- ▶ Recognise unique differences and skills of people with disability, as each person can respond to their disability differently and requirements of individuals with different disability types will vary.
- ▶ Collect data that disaggregates for disability, age and gender to maximise its usefulness to a range of decision-making groups.

Overview

This section outlines practical strategies to mainstream disability- and gender-inclusive strategies within the project cycle. It provides advice to support the implementation of inclusive approaches and practices through all phases of an eye health project. Content adheres to common approaches to Project Cycle Management (PCM). Terminology may vary between organisations and programs; however, the principles used in this resource are consistent with general PCM approaches.



Photo and story: CBM, Cambodia

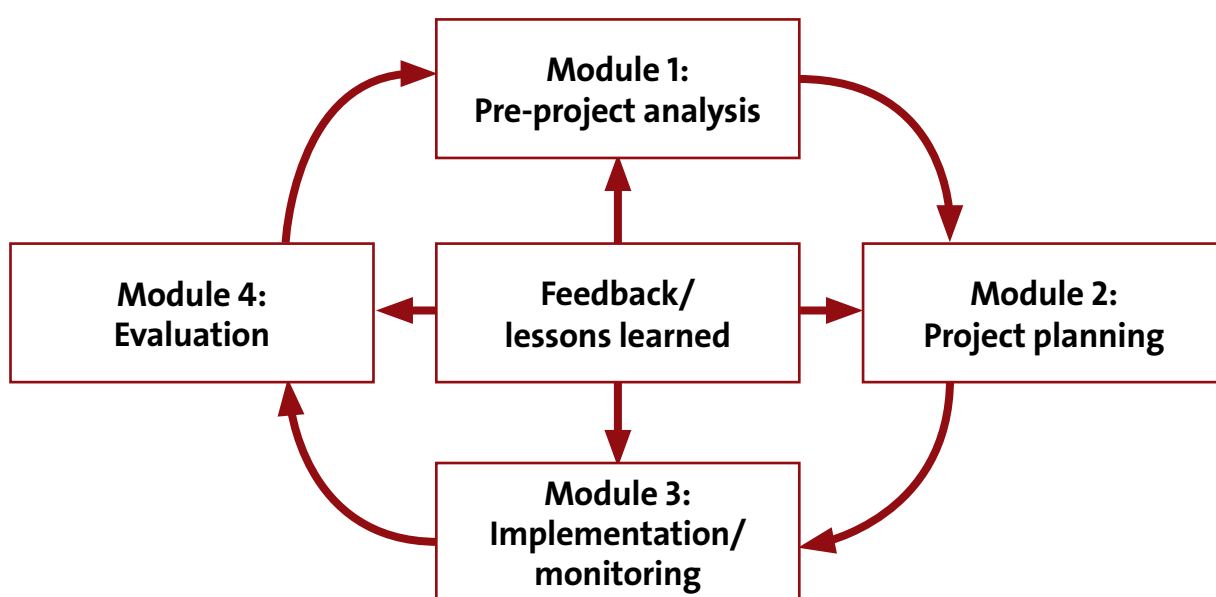
From exclusion to independence – Forty-year-old Mon Sry Menh was born with congenital cataracts. When Menh was born blind, her father did not know what to do. There was no local health service to visit where she could have been referred for surgery, and little understanding amongst her community that Menh could learn and work despite having a vision impairment. Menh eventually came into contact with a worker from a Community-Based Rehabilitation program and was able to access a small loan. She then received another loan through a CBM partner to start her own shop with her sister.

Menh is very proud of her shop, sharing, “It took me only two years to pay back all the loans and now we own this. I am so happy that I have a real job. It was very difficult before, but now I have an income. Neighbours who once teased me, now treat me well. They talk to me when before they would ignore me. I know where everything is and what the price is,” she said. “I’m sometimes a little slow with giving the money back to people, but they understand. I’ve been cheated a few times, but when I found out I chased them!”

Menh’s story highlights the importance of early referral for children and of connecting people with untreatable eye conditions to disability-inclusive development programs such as CBR in order to build independence and foster livelihood opportunities. It is also vital to work with communities to break down stigma and misconceptions about people with disability such as vision impairment.

Introducing the project cycle

When mainstreaming disability in the project cycle, it is important to consider the principles of disability inclusion, which are awareness, participation, comprehensive accessibility and the twin-track approach. All phases of the project cycle can become inclusive when entry points for disability inclusion are clearly identified and responded to. The EU project *Make Development Inclusive*³³ includes a comprehensive online resource of practical tools that can assist development programmers to ensure that their planning, implementation, monitoring and evaluation of programs include a disability perspective. Although some relate specifically to the EU program cycle, many can be extremely useful across a range of project or program cycle methodologies.



Found at www.inclusive-development.org/cbmtools/part3/index.htm

Pre-project analysis phase

The pre-project analysis phase brings together all relevant information for the proposed program and is an essential precursor to designing a project. Good pre-project analysis and design needs to be inclusive of people with disability from the start. It is important to seek out and communicate directly with a broad range of people with disability, their families and DPOs, providing opportunities for them to be active participants in analysing and planning the proposed program.

- ▶ Be wary not to group people with disability into a single ‘vulnerable group’ category or assume they all think the same without understanding their specific situations. There are many different stories of the lived experience of people with disability – know as many of them as possible.
- ▶ Logical frameworks are often required in support of program design as they are useful management tools. Their content is often reported as a requirement to donors and managers. A range of indicators reflecting disability inclusion should be in logical frameworks for disability-inclusive eye health programs. Indicators could include the number of people with disability accessing an eye health program and referrals to and from disability services and DPOs. This data should be disaggregated by disability type, age and gender. Additional indicators can relate to inclusive buildings, inclusion policies, staff awareness and attitudes towards inclusion within programs.
- ▶ Facilitate the active participation of people with disability as key stakeholders in community consultations, rapid assessments and other opportunities.
- ▶ Use accessible consultation venues and ensure information shared is inclusive of and accessible to people with a variety of disabilities.



Photo and story: CBM, Vietnam

Independence through access to assistive devices

– Phan Thanh Trung was born with low vision and attended Hanoi Nguyen Dinh Chieu School for students with a vision impairment. Initially he was taught to read Braille despite having some usable vision for accessing print. It was not until an ophthalmologist visited the school for eye examinations as part of its outreach activities that the school was recommended to use print with visual aids, including spectacles

and a magnifier. Mr Trung states, “My mobility, my reading and my life has been much improved and I have become more confident.”

The low-vision rehabilitation program funded by CBM and implemented by the Vietnam National Institute of Ophthalmology and Hanoi NDC School has given Phan Thanh Trung a richer life with greater independence and livelihood opportunities. In 2012, Mr Trung attended a short-term training course, ‘Rehabilitation for people with low vision’, conducted by a CBM low-vision advisor. He now has skills to detect low vision and train in independent living skills. He is working at the VNIO LV centre providing rehabilitation, visual acuity testing and training in the use of remaining vision to use aids and equipment.

Checklist: Pre-project analysis

- ☐ Are key stakeholders aware of the need to include people with disability for this phase of planning for the eye health program?
- ☐ Has a stakeholder analysis been conducted that includes disability, age and gender perspective?
- ☐ Are women and men with disability equally represented in the pre-planning phase?
- ☐ Are people with disability aware of their rights and entitlements to be included in the program?
- ☐ Are people with a broad range of disabilities participating in the pre-project analysis?
- ☐ Are people with disability attending regular consultations and stakeholder meetings, including playing a role in awareness-raising?
- ☐ Are venues fully accessible including water, sanitation and hygiene facilities?
- ☐ Are measures being taken to ensure all voices are heard equally?
- ☐ Have disability-specific data and relevant statistics been considered?
- ☐ Have people with disability been involved in necessary research or data collection?

Planning phase

The planning phase identifies the project's agreed objective and relevant strategies to reach the desired outcome. Here activities and resources are identified and organised to realise the project objectives in an effective and efficient manner. Including disability as a cross-cutting theme in the planning stage will ensure a more comprehensive and inclusive program.

- ▶ Consider how people with disability can participate in the eye health program, rather than just benefit from it. Consider opportunities in leadership, project management, government work and community-based employment. Key to participation is that people with disability are not just considered but are actually part of decision-making groups.

- ▶ Apply the principles of universal design. Ensure these are built in from the start to avoid additional costs. Also, check that planned project interventions and facilities are accessible for people with disability and other vulnerable groups, such as pregnant women and elderly people.
- ▶ Respond to possible negative attitudes that may prevent people with disability from being included. Individuals with disability are often the best people to determine this.
- ▶ Make disability-inclusion activities a line item in the budget. Experience suggests that placing disability in the budget will help keep it a priority. Ensure funds are available for mainstream inclusion and disability-specific support.

Checklist: Planning phase

- ☐ Does the project design clearly reflect specific requirements of people with disability?
- ☐ Is disability referred to in the Terms of Reference?
- ☐ Are there any anticipated negative impacts for people with disability?
- ☐ Have people with disability participated in the assessment and planning process?
- ☐ How will involvement of people with disability facilitate their empowerment?
- ☐ What strategies will the project apply in order to encourage people with disability and their families to actively participate in the project design (for example, outreach, budgeting, staffing, resources, venue and training)?
- ☐ Have physical, communication, attitudinal and policy barriers been considered?
- ☐ Are there disability- and gender-specific indicators built into the project design?
- ☐ As eye health programs are relevant to disability, has a separate appendix outlining the disability dimension of the project been attached to the plan?

“There are many children still needlessly in special schools, who read Braille with the papers pressed up to their eyes rather than with their fingers.”³⁴



Photo: Professor Jill Keeffe, University of Melbourne

Fostering empowerment through appropriate disability interventions – A boy with a vision impairment in a school for children who are blind in West Africa uses his remaining eyesight to read Braille, which he was taught to read through touch. Through low-vision training and devices, this boy could and should be taught to read large print, and be included in a mainstream school with his peers. It is essential that all children and adults with vision impairment receive a proper

assessment in a low-vision service, so they can make optimum use of the eyesight they do have. This in turn provides teachers and students with strategies to foster inclusion in a range of education settings.

Implementation and monitoring phase

This phase of the project is concerned with carrying out the project plan for objectives to be achieved effectively and efficiently. Including a disability perspective in this phase involves ensuring that the project is actually carrying out its plan and that people with disability are being included. This is done through monitoring both the project results and the budget line relevant for specific inclusion of people with disability. In addition, monitoring through effective data collection, including disaggregation by disability type, gender and age, is relevant in this phase.

- ▶ Ensure outreach activities are inclusive of people with disability and their families. In addition, monitor use of services by people with disability to ensure that women, men, boys and girls with disability are equally benefiting from the program. It is also important to ensure that staff have the skills and knowledge to be disability inclusive, including sensitivity to gender and age.
- ▶ Engage with local DPOs to seek their input and respond to barriers preventing full inclusion.

- ▶ Ensure that the monitoring, evaluation and learning (ME&L) system includes a disability perspective. This may involve reviewing different utilisation rates for people with disability, comparing these between women and men and boys and girls, and exploring the reasons behind these results.

Checklist: Implementation and monitoring phase

- ☐ Does the project's ME&L and data collection system include an overall disability perspective as well as disability- and gender-specific indicators?
- ☐ If people with disability have difficulties in accessing interventions, is there capacity to respond to these barriers?
- ☐ Are disability-specific budget lines being spent according to the plan?
- ☐ Are people with disability or DPOs continuing to be involved in consultation and decision-making about ongoing implementation of the eye health program?
- ☐ If a disability and gender perspective was not included in the analysis and planning phases, have steps been taken to respond to disability-inclusion and gender-sensitiveness in the implementation phase?

Evaluation phase

Evaluation is an activity that is time-bound and seeks to measure, in a systematic and objective way, how the completed or ongoing program has performed. The relevance and success is measured against the original design. Evaluation is undertaken in order to answer specific questions and give guidance to all stakeholders involved in the program. Asking disability- and gender-specific questions in an evaluation can provide valuable lessons. These can include assessing and evaluating whether people with disability were included or not, the perceptions of age and gender inclusion, the benefits or negative consequences associated with inclusion or exclusion, and evaluating the budget spent on agreed activities designed to improve disability inclusion. Most usefully, it can provide firm understanding of how to better ensure equitable inclusion of women and men with disability in future eye health programs.

Consider inviting a person with disability or a DPO to participate in the evaluation. This can assist in evaluating how the disability perspective was mainstreamed as a cross-cutting theme and how well disability-specific initiatives were implemented to ensure full and equal participation (the twin-track approach). Within this, determine whether data was gathered and disaggregated to identify numbers of participants, disability type, age and gender.

Checklist: Evaluation phase

- ☐ Are eye health program staff, relevant authorities and other stakeholders aware of the importance of including a gender-sensitive disability perspective?
- ☐ Do the evaluation and terms of reference include a gender-sensitive perspective inclusive of people with disability of all ages?
- ☐ Is there an equal representation of men and women with disability as stakeholders or facilitators in the evaluation?
- ☐ Are evaluation venues accessible for people with disability?
- ☐ Does the program reflect early intervention measures for children, with a particular focus on girls with disability throughout the project cycle?
- ☐ Is there a proactive approach to child protection through the project cycle?
- ☐ Does the ME&L system include indicators and other disability measurements?



Photo: CBM, India

Disability-inclusive training – In India, a woman who is blind receives computer training in a centre that uses Braille signage and other accessible information to ensure training is inclusive. It is important that people with disability receive skill development in appropriate livelihood opportunities. This ensures that the capacity of each individual with a disability is harnessed and their contribution to the work force is valued.

Women and children with disability in the project cycle

Many eye health programs are aware of the need to be responsive to the particular rights, participation requirements and protection of women and children. Often women and children with disability experience increased exclusion and challenges in accessing services. Disability-inclusive, child- and gender-sensitive practices should understand and eliminate barriers that hinder women and children from accessing all aspects of an eye health program. It is also important to keep in mind that some disability groups will be more vulnerable than others and particular attention needs to be given to protection and the facilitation of empowerment of women with mental health conditions and intellectual disabilities. The following actions can be undertaken to support inclusion and protection of women and children with disability:

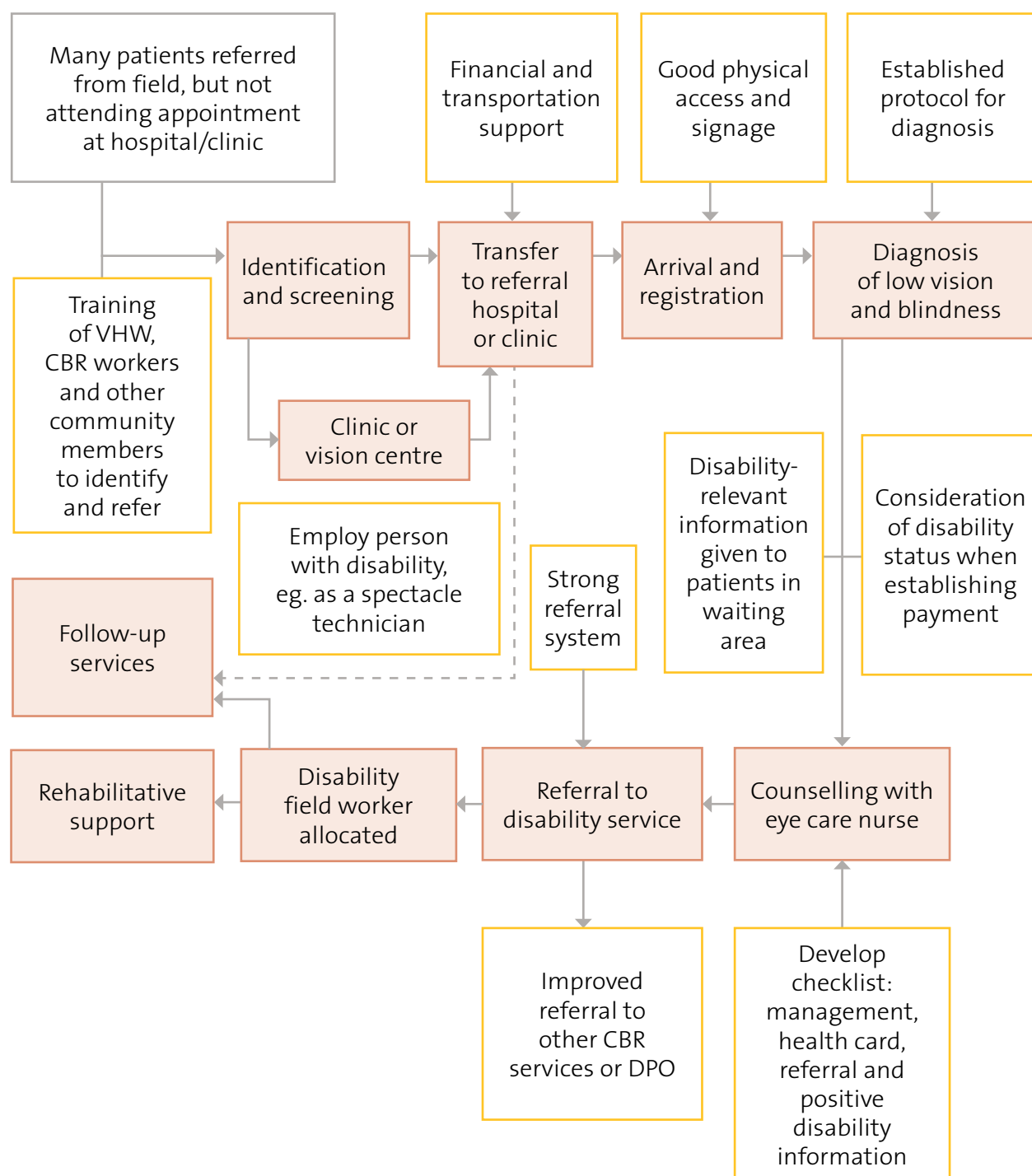
- ▶ Consult with women with disability to identify and address their specific access barriers.
- ▶ Train eye health program staff on the impact of disability on women and children, along with useful strategies to respond to barriers.
- ▶ Employ women with disability in the eye health program.
- ▶ Connect with a DPO that can represent the rights of women and children with disability.
- ▶ Appoint a coordinator for disability inclusion who understands gender-sensitive practice. This may be a part-time role for an existing staff member.
- ▶ Ensure the eye health program has a child protection policy and that all staff are trained in the particular vulnerabilities of children with disability.
- ▶ Collect, disaggregate and analyse data by gender, age and disability.
- ▶ Develop networks and two-way referral points with primary health care, rehabilitation, education and DPOs, ensuring disability, age and gender-sensitive practice.
- ▶ Ensure that women and children with disability who cannot be assisted through medical intervention receive counselling and referral to opportunities in health, education, rehabilitation, livelihood and social inclusion.

Disability-inclusive approaches in an eye health program

Caritas Takeo Eye Hospital in Cambodia has implemented a range of initiatives throughout the program cycle to support access for all community members including people with disability. Hospital management has been supported in a number of initiatives that explicitly include people with a wide range of impairments. Within the Takeo district it was found that people with disability, including vision impairment, were often not accessing eye health programs. It was also found that those with permanent vision impairment were not always referred to community-based support and access to wider opportunities. In response, key hospital staff worked proactively with all staff, disability organisations and community members to improve access to all their programs, including outreach services. This work has had positive outcomes for people with disability and their families, and also for other vulnerable groups. Access has been improved. Referral pathways, both to the hospital and from the hospital to other services, are now well established. In addition, people with permanent vision impairment have access to a low-vision service at the hospital, together with wider opportunities in education, rehabilitation, livelihood, social inclusion and empowerment.

The flow chart on the next page demonstrates the process of disability-inclusion at Caritas Takeo Eye Hospital.

Flow chart of disability inclusion at Caritas Takeo Eye Hospital, Cambodia



Established process



Example processes of disability inclusion



Photo: CBM, Niger

Overcoming disability related stigma – Fati Hassane lives in a low income settlement in Niger, West Africa. She acquired leprosy 20 years ago at the age of 40 and now has physical impairments as a result of this condition. She also has vision impairment due to untreated cataracts and another eye condition. Fati explained that, “In the beginning it was very hard, I had to be fed by others. People didn’t want to touch me because they thought they’d catch the leprosy.” Fati highlights the stigma she and others have experienced, stating, “We definitely did not feel accepted in this society”. Fati acknowledges that in the past when the chief of the community called a meeting, people with leprosy were not informed”.

Following CBM’s involvement, Fati received an eye examination, however treatment was not possible. Fati and 19 other women with leprosy then formed a co-operative and received CBM Micro Enterprise loans and livelihood training. Fati now has a small farm and hires out a donkey cart while others sell vegetables and operate small shopping stalls. In addition, CBM has ensured children in Fati’s community have been immunised, quickly have eye infections treated, and that families’ approaches to nutrition, sanitation, hygiene and basic life skills have been strengthened. Community education also occurred within Fati’s village to raise awareness that leprosy is not contagious. “Now people understand,” she says. “They look at me differently, they treat me like family, now there’s no discrimination”. Fati’s story highlights the stigma experienced by some people with disability. Stigma can reduce community acceptance and life opportunities including access to health programs.

Checklist: Disability inclusion in the project cycle

- ☐ Have eye health program staff received training on specific requirements people with disability may have?
- ☐ Has disability awareness and knowledge increased amongst program staff?
- ☐ Do people with disability have a better understanding of their rights and entitlements?
- ☐ Were people with disability able to access the full range of eye health services offered?
- ☐ Is there a child protection policy that is sensitive to the vulnerabilities of children with disability?
- ☐ Is the program responsive to the particular requirements of women and children with disability?
- ☐ Do people with a wide range of disabilities have the opportunity to be involved as active participants in decision-making processes (for example, through speaking at meetings and direct communication with service providers)?
- ☐ Has the community's knowledge regarding disability rights and participation strategies increased? If so, how?
- ☐ Have eye health program staff formed a deeper respect and understanding of people with disability and their families, including decreased stigma and discrimination and increased appreciation of capacities and contribution?
- ☐ Have organisational policies, procedures and program decisions been reviewed and updated to be disability inclusive?
- ☐ Are there partnerships with disability organisations?
- ☐ What are the lessons learned and recommendations for addressing disability-related barriers in the future?

Useful resources and websites: Disability inclusion in the project cycle

Inclusive Development Newsletter. CBM.

www.cbm.org/i/inclusive-development-newsletters-300575.php

Inclusion Made Easy: A quick program guide to disability in development. CBM (2012).

www.cbm.org/inclusive-development

Make Development Inclusive: How to include the perspectives of persons with disabilities in the project cycle management guidelines of the EC. (2008).

CBM International.

www.includeeverybody.org/pdfs/Make_Development_Inclusive_A_Practical_Guide_PCM.pdf

Make Development Inclusive: How to include the perspectives of persons with disabilities in the project cycle management guidelines of the EC. Part 3 –

The Online Toolbox.

www.inclusive-development.org/cbmtools/part3/index.htm

section 6

DISABILITY INCLUSION IN CURRICULUM DEVELOPMENT AND TRAINING

Key messages

- ▶ Promoting disability information within training courses will help to improve disability-inclusive practices in eye health programs.
- ▶ Knowledge on disability, including age and gender dimensions, builds confidence in eye health staff.
- ▶ Strategies to respond to barriers to inclusion, along with experience in how to communicate with people with disability, are important for genuine disability inclusion.
- ▶ Incorporating information about the needs and rights of people with disability in training curricula for eye health workers and other medical staff is a vital step in achieving greater disability inclusion.

Overview

This section offers a rationale for disability inclusion in training for eye health practitioners. Underpinning the importance of sound knowledge and training is the ever-increasing evidence base for disability inclusion, access to inclusionary strategies and a universal agreement that people with disability have rights and need to be included in all development programs. Training strategies, ideas for sourcing presenters with disability and key information to include in a training session are outlined in this section.

Training considerations

- ▶ Provide explanations on the nature and causes of disability according to the International Classification of Functioning, Disability and Health (ICF).
- ▶ Highlight the evidence base related to causes of impairment and use this to dispel myths that may be held by some community members about disability.
- ▶ Share ideas on how to communicate with people with disability, particularly people with an intellectual disability, hearing impairment or vision impairment.
- ▶ Provide practical identification of attitudinal, physical, communication and policy barriers for people with disability in eye health facilities and how these barriers can be minimised or eliminated. For example, share ideas on strategies to address financial barriers that affect people with disability in developing countries who make up 22% of the poorest people.³⁵
- ▶ Provide relevant information on rights, including the UN Convention on the Rights of Persons with Disabilities.
- ▶ Develop knowledge of the existence of disability services in the community such as CBR and identify how they benefit people with disability, including through daily living support, mobility training, child development, educational support, low-vision aids, Braille services, support for livelihoods, self-help groups and especially inclusive education.
- ▶ Identify relevant social protection measures such as health cards and insurance, and disability pensions.
- ▶ Build an understanding of the potential of people with disability. This can be achieved by having a person with disability (who may be from a DPO) present at a training session.
- ▶ Build a basic understanding of the gender dimensions of disability and how these affect ways in which women and men with disability experience exclusion differently and thus face different barriers to inclusion.

Photo and story: Vision 2020 Australia, Samoa

Returning to school – Misiuepa is 14 years of age and lives in Samoa. Due to a disease that caused nerve damage to his eyes, he became blind and was ultimately forced to drop out of school because he could not see the blackboard or read his books. Thanks to an Australian Government funded program, Misiuepa has now been able to return to school with the support of a teacher's aide and is learning Braille. After receiving assistance to be included in his school, he now has aspirations to become a teacher. His ultimate dream is to build inclusive education opportunities in Samoan schools so that other children with a vision impairment can have access to educational opportunities. Support and training to foster inclusion in mainstream schools ensures that children who acquire a vision impairment can return to their local school with their friends. When disability management skills are embedded in student and teacher training, community awareness about the capacity of people with disability is improved, allowing for positive community support.



Communicating with people who are blind or vision impaired

The following points are techniques to keep in mind when meeting with a patient who is blind or vision impaired. In addition, contact a DPO and ask for a presenter with a vision impairment to share their experiences and strategies for communication.

- ▶ Say your name when introducing yourself.
- ▶ Use the name of the person with low vision or blindness so they know you are talking to them.
- ▶ Face and talk to the person with a vision impairment and not any accompanying individuals.
- ▶ Be specific in giving directions such as saying left or right rather than using physical gestures and pointing to go here or over there.
- ▶ Identify the room you are in if the person cannot see enough to recognise their surroundings. For example, state if you are in a waiting room or consultation room.

- ▶ Describe the layout of the room, especially where there is technical equipment (such as an operating room).
- ▶ Identify and name others in the room 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.
- ▶ Tell the person if you leave the room.
- ▶ 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 surroundings.

When guiding a person who is blind or vision impaired

- ▶ Ask if assistance is required.
- ▶ Determine preferred instructions for sighted guide by asking the individual.
- ▶ Be aware of other disabilities that an individual may have and how they may impact safe navigation around the building.
- ▶ Offer to act as sighted guide to a new location by allowing the person with a vision impairment to hold onto your elbow and stand one step behind. Guide their hand to rails, doors or the back of a chair as relevant.
- ▶ Walk at an average pace.
- ▶ Announce when you are arriving at a turn, door, step or obstacle.
- ▶ Provide information when at a change in surface and when travelling up or down a flight of stairs.
- ▶ Guide one hand of the person to the back or arm of a chair or to the edge of a table when you have reached the new location.



Photo and story: Score Foundation, India

Score Foundation training for eye health programs in India – Mr George Abraham is the founder of Score Foundation and has a vision impairment. Part of his role includes training eye doctors in disability inclusion. A number of training events such as lectures and workshops have been delivered across the eye health sector in India. By early 2013, he reported attendance by 250 eye care professionals. Although a number of ophthalmologists initially did not see the workshops as important, key eye practitioners valued the sessions and recognised the importance of disability inclusion in their work. As a result of the training, many hospitals acknowledge the need to conduct similar sessions at their community clinics. The Score Foundation also realised the importance of conducting sessions on specific areas such as use of assistive technologies. The discussions from some of the workshops have led to the idea of establishing model vision rehabilitation centres at hospitals such as Shroff and Gandhi Eye Hospital. In addition, a documentary film has been developed that demonstrates employment possibilities and life opportunities for people with a vision impairment and blindness. The English version of the documentary can be found at www.youtube.com/watch?v=nYhS8veosD4 and the Hindi version at www.youtube.com/watch?v=rB_S4mL_TtY

Checklist: Disability-inclusive training

- ☐ Has education been provided on the nature and causes of disability?
- ☐ Have possible negative perceptions and myths about disability been dispelled?
- ☐ Has education been provided on attitudes among professionals and community members related to disability, including gender dimensions? Remember that attitudinal barriers can be the most significant barriers to overcome.
- ☐ Are people with disability and DPOs used as a source of presenters for training purposes? Remember that some DPOs can be disability specific so be clear on your training purpose.
- ☐ Does the training include awareness of the protection and rights of people with disability, including the particular vulnerabilities of women and children with disability?
- ☐ Does training improve staff capacity to identify the potential range of barriers to men and women, boys and girls and elderly people with disability in accessing eye health programs?
- ☐ Does training focus on strategies to minimise or eliminate access barriers (including physical, communication, attitudinal and policy barriers)? For example, are practitioners trained in ways to respond to financial barriers faced by many people with disability?
- ☐ Has training been provided in effective and respectful communication with all people with disability across all impairment groups?
- ☐ Does training include knowledge of local referral services and entitlements for people with different impairments?
- ☐ Is there training for all practitioners in child protection including strategies to create a child-safe and child-friendly environment?
- ☐ Do key practitioners have counselling skills for patients with a newly acquired untreatable eye condition?

Useful resources and websites: Disability inclusion in curriculum development and training

Disabled People International.

www.dpi.org

Handicap International publications.

www.handicap-international.org.uk/resources/library

Inclusion Made Easy: A quick program guide to disability in development. CBM (2012).

www.cbm.org/inclusive-development

Life Does Not Stop Here [Documentary]. (2012). Score Foundation.

www.youtube.com/watch?v=nYhS8veosD4 (English);

www.youtube.com/watch?v=rB_S4mL_TtY (Hindi)

section 7

ORGANISATIONAL STRENGTHENING – MAKING DISABILITY INCLUSION A REALITY IN EYE HEALTH PROGRAMS

Key messages

- ▶ Disability inclusion often only requires small changes to the way staff work.
- ▶ Strengthen the organisation by building on what the eye health program is already doing well.
- ▶ Recognise that staff may require new knowledge and skills to better address the needs of people with disability, including gender and age dimensions.
- ▶ Organisations should work closely with people with disability, DPOs and relevant services when reviewing programs.
- ▶ Support from organisational leadership is required to mainstream gender- and age-sensitive disability-inclusive development practices.
- ▶ Get started, have conversations and raise awareness about disability and its gender and age dimensions.
- ▶ Each eye health program will follow a slightly different path leading to its own organisational strengthening.

Overview

This section includes advice and ideas on how to improve disability inclusion across eye health programs. Building disability-inclusive development practice into eye health organisations is an ongoing process, takes time and can involve a number of approaches. Leadership support, a disability champion or working group, and individual disability-specific programs can all play a role in supporting an organisational approach to disability inclusion.

Awareness of disability inclusion across an organisation

Awareness-raising is often a necessary first step, and may need to occur differently with management, support staff, medical practitioners and boards. Raising awareness and building knowledge should be ongoing throughout the program. Answering the question of why an eye health program should be disability inclusive occurs many times. Be prepared to respond to this question when the many competing priorities of the program are highlighted. Importantly, raise awareness regarding disability within the leadership of the program. Support from leadership and boards is essential for progress.

Embedding disability-inclusive practice leads to valuable outcomes both in broader development practice and in life opportunities for people with disability. It is useful to consider the following points when seeking to mainstream disability-inclusive practice across an organisation:

- ▶ ‘Disability champions’ – individuals who have advocated for disability-inclusive practices in their organisation – have been essential to changes in many eye health programs. Look for like-minded colleagues.
- ▶ Establish a formal or informal disability or inclusion working group.
- ▶ Seek support from other services that have been successful in disability inclusion and identify the strategies they have used.
- ▶ Organise training in disability and development and include a person with disability as part of the training being delivered.
- ▶ Encourage key staff who attend external training regarding disability and development to then share with all eye health program staff.

- ▶ Appoint a disability-inclusion officer, who can be part-time. Ensure this point person has days dedicated within their position description to support disability and inclusion within the eye health program.
- ▶ With leadership support, develop an inclusion/disability policy. Source sample disability policy documents from other health programs.
- ▶ If a disability-in-development network group exists in your area, encourage membership from key eye health program staff.
- ▶ Identify and promote existing disability-inclusive practices within the program.
- ▶ Include information or a story about disability in an eye program publication or journal.
- ▶ During planning, seek out funding opportunities that support disability-inclusive development programs.
- ▶ Use or develop disability-inclusive age- and gender-sensitive data collection tools.
- ▶ Actively try to recruit people with disability into the program.

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“Doing nothing is not acceptable. We may lack the answers ourselves, but all we have to do is to ask the people concerned.” ³⁶
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Photo and story: Royal Australasian College of Surgeons, Timor Leste

Orientation and mobility training for people who are blind or vision impaired in

Timor Leste – It is important that comprehensive eye health services include rehabilitation and, in particular training in mobility skills for those with irreversible eye conditions. Since 2001, the Royal Australasian College of Surgeons (RACS) has worked in Timor Leste to provide life-changing eye surgery. More recently RACS has expanded its function to support the delivery of a training program in orientation and mobility (O&M) instruction. Senor Dominggos Gusmoa, the president of the local blind union (ETBU), is vision impaired and plays an active role in O&M stakeholder forums as well as working closely with O&M training specialists in the development of their training plans. As trained O&M instructors, Senor Dominggos and other community members with a vision impairment have become positive role models. A train-the-trainer approach has ensured capacity building of locals including women with a vision impairment. Fostering the independence of women and girls in safe mobility skills is critical due to a higher risk of sexual harassment and abuse. In addition, wherever possible, the local O&M trainers accompany the outreach eye teams during their pre-screening activities to provide O&M services to patients unable to be treated by surgery. Training in O&M skills in open spaces such as the waterfront in Timor Leste's capital, Dili, is also used as an opportunity to educate community members about vision rehabilitation. The O&M component of RACS's program demonstrates an organisational response to capacity development of local people with disability.

Disability-inclusive practice reflections

The practice of disability-inclusive development often requires new learning and reflection. Time and resources are important to improve confidence in this process. Embedding disability inclusion across a program involves a change in hearts and minds. Typically, approaches that involve both staff and leadership support work best. It is, however, often a single champion who starts a conversation around disability who gets the ball rolling. The process of supporting disability-inclusive development practice can be different in each program, so a tailored approach may be required.

Improving disability inclusion in an eye hospital

An evaluation of an African eye hospital found it was doing high quality work. As a result the hospital had become the ‘victim of its own success’. People with resources travelled from all over the country for treatment but a survey discovered there were very poor people living within a few kilometres of the hospital who were bilaterally blind due to un-operated cataracts. Fees charged by the hospital were important for its viability, but the way the fees were applied excluded these poorest people with bilateral blindness from accessing their ‘right to sight’. A fund for poor patients created through a percentage of fees existed, but was inadequately applied. An evaluation led the hospital to conduct a wider audit on disability inclusion. As a result, a committee was put in place to advise hospital management. The terms of reference for the committee stated its membership should include at least one senior staff member and also a person with disability. The following are recommendations identified by the committee:

- ▶ Increased encouragement and guidance from hospital management to appropriately use the ‘poor patient fund’, resulting in improved usage.
- ▶ Improved wheelchair access to the buildings and latrines, and the removal of obstacles for people with a vision impairment, benefiting all who visited the hospital.
- ▶ Improved cleanliness of latrines as mobility of some patients was via crawling.

Patients were provided with various attractive brochures and posters describing services to display in their community, leading to increased referrals in target districts.



Photo and story: CBM, Vietnam

Reducing incidence of avoidable blindness – Thanh Hoa Eye Hospital in Vietnam is working to reduce avoidable blindness in numerous highland districts in Thanh Hoa Province. The mountainous environment makes access to health care difficult, especially for people with disability, including women and children. Through a partnership with CBM in the AusAID-funded Vietnam Australia Vision Support Program (VAVSP), the hospital is working towards accessible disability inclusion through providing comprehensive services at a local district level. Disability-inclusive approaches include training staff in rights, making buildings physically accessible, home examinations for people unable to attend a clinic, and multiple options for sharing information (including radio announcements, pictures and large print). In addition, linkages have been made with other services for education and employment for improved referral processes.

Do Giang Nam (wearing cap) is a refractionist and spectacle technician from a district eye unit who completed disability inclusion training. He said, “After training... I am aware that people with disability need better care from society, from inclusive infrastructure to policies for vulnerable groups. In my thinking, a developed society is the one with a positive, comprehensive and inclusive health care system.” Nam also explained that he has shared his learnings with his colleagues and consulted the board members of his district hospital about disability-inclusion processes, including making changes to the building to make it more accessible.

Disability inclusive practices in eye health programs

ROLE IN EYE HEALTH PROGRAM	EXAMPLES OF IMPROVEMENTS TO STRENGTHEN DISABILITY INCLUSION IN EYE HEALTH PROGRAMS
Eye health program managers and leaders	<ul style="list-style-type: none"> ▶ Managers to develop child protection policy and processes to safeguard children. ▶ Leadership staff to develop greater understanding of the needs and rights of people with disability, using a rights-based and gender-sensitive approach. ▶ Commit time and resources to understanding and learning about disability inclusion. ▶ Ensure time is made available for key service processes to be reviewed for improved disability inclusion. ▶ Work with people with disability and DPOs to train staff on disability inclusion in programs. ▶ Employ people with disability in the organisation. ▶ Appoint a disability inclusion officer or make it part of an existing staff member's role. ▶ Develop a Disability Policy and a Disability Action Plan for the organisation. ▶ Ensure premises are accessible and clean for all people with disability.
Eye health program staff	<ul style="list-style-type: none"> ▶ Improve knowledge through a rights-based understanding of disability inclusion. ▶ Participate in reviews of program processes. ▶ Document and train on key activities to ensure people with disability receive high-quality services including treatment, counselling and referrals. ▶ Ensure patient information is accessible to all people with disability. ▶ Ensure all staff have been trained in appropriate methods to assist and guide people with disability such as patients with a vision impairment and those using a wheelchair.

ROLE IN EYE HEALTH PROGRAM	EXAMPLES OF IMPROVEMENTS TO STRENGTHEN DISABILITY INCLUSION IN EYE HEALTH PROGRAMS
Community health workers	<ul style="list-style-type: none"> ▶ Establish strong relationships with eye health programs and assist in promotion and prevention messages to all people in communities, including people with disability. ▶ Establish and ensure good knowledge of referral processes for people with vision and other impairments to eye health and other programs. ▶ Ensure adequate information is provided on costs, time and expectations for rehabilitation, vocational training and education programs.
CBR field workers	<ul style="list-style-type: none"> ▶ Establish strong working relationships with eye health program staff. ▶ Ensure two-way referral processes. ▶ Consistently follow up with patients referred from an eye health program to a CBR service. ▶ Refer clients as appropriate to eye health services and offer assistance for follow-up appointments.
Ministry of Health and PBL staff	<ul style="list-style-type: none"> ▶ Improve knowledge and support regarding disability inclusion in health services. ▶ Support disability inclusion through promoting and delivering appropriate training across the primary health care system and with other relevant ministries. ▶ Employ people with disability in the health system.
Disabled People's Organisations (DPOs)	<ul style="list-style-type: none"> ▶ Establish relationships with eye health programs, sharing information that can be passed on to patients regarding DPO membership. ▶ Offer to take part in consultations and trainings within the program.
Local communities	<ul style="list-style-type: none"> ▶ Improve knowledge across communities of the needs, rights and potential of people with disability. ▶ Raise awareness of the benefits of health programs for people with disability. ▶ Encourage and support community members with disability to access eye health programs.



Front cover – photo and story: CBM, Cambodia

Referral processes in a disability-inclusive eye health program – Bok Sokah is five years of age and was referred by a disability service, CDMD, to Takeo Eye Hospital where he was diagnosed with cataract and a lazy eye. Sokah's referral to the eye hospital was difficult due to his deafness and inability to talk. From the time of Sokah's birth, his mother Nget did not receive much help from the rest of her family, recognising that they loved him but did not know what to do. "They say things like 'It must be your fault that he is like this.' " Before contact with CDMD, Sokah did not receive any support for his impairments nor did he go to school. "My son always has to stay with me. This means that I can't go to work as much as I'd like to. It means that our income is low and it makes it hard to buy food and things we need." Due to Caritas Takeo Eye Hospital's ability to include people with a range of disabilities, Sokah was treated for his eye conditions including removal of cataracts. He was also referred to other services to provide support for his deafness and speech barriers. Sokah left the hospital with the ability to see and is now enrolled in his local school where through CBR he receives support for speech therapy and access to inclusive education. Nget has also been able to return to work to improve their family's income. These interventions have not removed all Sokah's impairments, but they have addressed some disabling aspects of his deafness and speech impairment.

Checklist: Organisational responses to disability inclusion

- ☐ Are there internal champions, leadership supporters and/or regional partners interested in disability?
- ☐ Has a disability-inclusion officer been appointed? This may be a part-time allocation within an existing staff member's role.
- ☐ Can disability be linked to organisation vision/mission statements (such as 'reaching the most marginalised people')?
- ☐ Are there internal strategies and policies where disability can be incorporated?
- ☐ Is there capacity to form a disability or inclusion committee?
- ☐ Have relevant international conventions such as the CRPD been identified along with other compliance instruments?
- ☐ Have the most relevant components of the eye health program been identified where disability is most likely to be included?
- ☐ Has leadership support been harnessed where disability can be included in policies, programs, submissions and partnership agreements?
- ☐ Are internal positions advertised through disability networks and are people with disability encouraged to apply?
- ☐ Have roles been identified where gender- and age-sensitive disability inclusion can be written into the position description with a time allocation?
- ☐ Have resources been allocated to foster disability inclusion across the eye health program?
- ☐ Have successes been highlighted and shared with the sector?
- ☐ Has research been undertaken to gather information on the prevalence, impact or lived experience of disability and its gender and age dimensions?
- ☐ Have disability-in-development groups been joined for inclusion ideas and meetings with other eye health programs and relevant organisations?

Useful resources and websites: Organisational inclusion for people with disability

Ask Source resource library.

www.asksource.info/res_library/disability.htm

Inclusive Development Newsletter. CBM.

www.cbm.org/i/inclusive-development-newsletters-300575.php

Community-Based Rehabilitation: CBR Guidelines. (2010). World Health Organization.

www.who.int/disabilities/cbr/guidelines/en/index.html

Disabled People International.

www.dpi.org

Handicap International publications.

www.handicap-international.org.uk/resources/library

Inclusion Made Easy: A quick program guide to disability in development.

Part A, Section 4. (2012). CBM. www.cbm.org/inclusive-development

International Disability and Development Consortium (IDDC).

www.iddcconsortium.net/joomla

Make Development Inclusive website.

www.make-development-inclusive.org

Mobility International USA (MIUSA). www.miusa.org

World Report on Disability. (2011). World Health Organization/World Bank.

http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf

Acknowledgments

Many hours of research and expertise have gone into the development of the *Inclusion Made Easy in Eye Health Programs* guide. We are grateful for the contribution of eye health and disability practitioners worldwide, in particular, the work of many people in CBM and its field partner organisations, the CBM-Nossal Partnership for Disability Inclusive Development, members of Vision 2020 Australia and their field partners, and all our co-branding agencies, together with other groups and individuals.

We would also like to acknowledge the Australian Government's support for the first edition of this guide under the Avoidable Blindness Initiative – supported by Australian Agency for International Development, AusAID. The first edition was written and edited by Pauline Kleinitz (formerly CBM-Nossal Partnership for Disability Inclusive Development), Gail Ormsby (formerly CBM Australia), Cristy Gaskill, Joanne Rowe and David Lewis.

This edition, developed through CBM Australia, has been written and edited by Joanne Webber and David Lewis, with production supported by Shannon McSolvin.

Additional contribution, guidance and feedback from:

CBM International Medical Eye Care Advisory Working Group: Prof. Colin Cook, Dr Richard Bowman, Dr Irmela Erdmann, Dr Pedro Gomez, Prof. Harpreet Kapoor, Dr Dominic Misquith, Dr Babar Qureshi, Dr Demissie Tadesse, Karin Van Dijk, Dr Andrea Zin with Dr Manfred Moerchen and Dr Sara Varughese.

Our co-branding agencies:

Brien Holden Vision Institute (BHVI); Centre for Eye Research Australia (CERA); the Fred Hollows Foundation (FHF); Helen Keller International (HKI); International Agency for the Prevention of Blindness (IAPB); International Centre for Eye Health (ICEH); Light for the World; Lions Sight First; LV Prasad Eye Institute; Orbis; the Royal Australasian College of Surgeons (RACS); the Royal Australian and New Zealand College of Ophthalmologists (RANZCO); Sightsavers; VISION2020: The Right to Sight; Vision2020: The Right to Sight, Australia; and the World Blind Union.

Other people include, but are not limited to:

George Abraham, Kathy Al'Jubeh, Sirin Atsilarat, Sally Baker, Umesh Baurai, Diofo Beido, Monika Brenes, Dr Sandeep Buttan, Prateep Cakraborty, Liz Cross, Aurelien Dayde, Gunawathy Fernandez, Dr Marion Heap, Chelsea Huggett, Jill Keeffe, Christin Lidzba, Nathalie Maggay, Manjula Marella, Silvana Mehra, Shiva Mohan, Emma Pearce, Murali Pradmanabhan, Dinesh Rama, Sachu Ramalingam, Valerie Scherrer, Te Sereybonn, Nagarathna Subramanya, Glenna Tan, Kirsty Thompson and Soumana Zamo.

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Photo: CBM, India

Social inclusion for people with disability –

In India, Joseph Eye Hospital has been awarded for their long-standing efforts in providing the highest number of employment opportunities to people with disability in Tamil Nadu State. The hospital's director, Dr C A Nelson Jesudasan, received this gold award for the 12% of Joseph Eye Hospital staff with disability. From the 1950s, the hospital's founder ensured that people with permanent eye conditions could access education opportunities. The hospital continues this legacy by ensuring access to vision rehabilitation and broader services, including vocational training and social inclusion opportunities for people with a range of disabilities.

