count me in

Include people with disabilities in development projects

A practical guide for organisations in North and South

By Paulien Bruijn, Barbara Regeer, Huib Cornielje, Roelie Wolting, Saskia van Veen and Niala Maharaj

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Who is disabled?

If you fail to see the person but only the disability,
then who is blind?

If you cannot hear your brother's cry for justice,
who is deaf?

If you do not communicate with your sister but separate her from you,
who is disabled?

If your heart and your mind do not reach out to your neighbor,
who has the handicap?

If you do not stand up for the rights of all persons,
who is the cripple?

Your attitudes towards persons with disabilities may be our biggest handicap,
and yours too.

Tony Wong

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Authors' note

'Disability inclusion' has become yet another topic on the overflowing agendas of overburdened managers and programme officers at development organisations. But have no fear: this booklet will not add to your burdens. In fact, it will lighten them.

What we have learnt from experience – and what we want to share with you – is that including persons with disabilities in the target group of your organisation doesn't require launching a whole new additional programme. It can be achieved within existing activities, training schemes and policies. This guide shows you how. It contains simple, practical steps you can take to include persons with disabilities in your activities.

This guide is chock-full of suggestions, real-life examples and experiences to inspire development practitioners to take action. It is aimed at staff at head offices of development organisations in the North, as well as those working at implementing organisations in the South. We hope it will have value for donors, NGOs, government organisations, policy-makers and, ultimately, for people with disabilities themselves.

Different factors can trigger an organisation to start working on the inclusion of people with disabilities. Primarily, there is the UN Convention on the Rights of Persons with Disabilities, which motivates organisations to start including people with disabilities in their programmes. This is a logical consequence when countries ratify the Convention. Sometimes the process of inclusion starts with a manager who has a disabled child and puts the topic on the agenda. In other cases, organisations evaluate their own programmes and discover that people with disabilities do not benefit from their humanitarian relief work. Some organisations want to work on inclusion of persons with disabilities because it is implied in their overall vision and mission: for example, education for all. There are also organisations where the process starts with a request from a donor.

What is the point of this guide?

Whatever the reason, this guide offers a jump-start. It provides inspiration material that enthusiastic individuals can use to put the topic of disability inclusion on the agenda of their organisations. But it also gives essential information on how inclusion can be anchored within organisational structures and policies.

Why do you need it?

Our own story

Four years ago, three Dutch development organisations got together and decided they should stop talking about the inclusion of persons with disabilities and start doing something to make it happen. This resulted in a

How did this guide come into being?

capacity-building programme for partner organisations in India and Ethiopia on how to include persons with disabilities in mainstream development programmes. Other Dutch NGOs joined in, along with their own partner organisations in these two countries.

→ *Based on real-life experience*

At the beginning, our focus was primarily on the inclusion of people with disabilities in development projects. But along the way we realised that the inclusion we were seeking not only required attitudinal change, but also organisational change. It was not only about inclusion in projects and programmes; it was also about our own organisational values, systems and policies. There were not only barriers within our projects, but also barriers in our own offices and websites that prevented persons with disabilities from equal participation.

→→ *Policy change is needed*

We therefore launched a 'Thematic Learning Programme' (TLP) on the inclusion of persons with disabilities in January 2011. This was sponsored by PSO, a Dutch capacity-building organisation. Thirteen donor organisations (six Dutch mainstream NGOs; three Dutch disability-specific NGOs; and four mainstream NGOs from other European countries – the UK, Germany, Belgium and Denmark) and 21 implementing organisations in Ethiopia and India participated.

Participating organisations formulated their own learning questions and action plans to promote the sustainable inclusion of persons with disabilities in their own programmes and organisations. The guide you now hold in your hand is one result of this learning programme. It is based on the real-life experiences of these organisations. We hope our experience will inspire others to start their own journeys towards equal participation of persons with disabilities.

→ *Definitions are important*

Introducing the content

Part One of this publication provides a vital introduction to the topic of disability and development. It can be very helpful if you are new to this issue. It challenges conventional perspectives on disability and compels questioning of popular definitions in this field. Here, we lay out the human rights perspective on disability and clarify the need for disability-inclusive development programmes.
Part Two explains the steps that can be taken to include persons with disabilities in regular development programmes. This chapter is extremely relevant to development practitioners involved in the design, implementation, monitoring and evaluation of projects and programmes, and those involved in training staff.

Part Three addresses how organisations can anchor the topic of disability inclusion within their own policies, systems and structures. This is interesting for policy-makers, monitoring and evaluation officers and senior management. This chapter also includes a practical test for discovering how disability-inclusive your own organisation is.

Introducing the writers

Paulien Bruijn, inclusive development coordinator, SeeYou Foundation
Huib Cornielje, disability consultant, Enablement
Niala Maharaj, coordinating editor
Barbara Regeer, assistant professor, Athena Institute, VU University, Amsterdam
Saskia van Veen, researcher, Athena Institute, VU University, Amsterdam
Roelie Wolting, disability consultant, Dutch Coalition on Disability and Development

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We would also like to thank Joyce den Besten, who cheerfully helped in the production of this booklet, as well as the following research students at the VU University, Amsterdam, who provided us with case stories from the Netherlands, Ethiopia and India: Heleen Troost, Ineke Caubo, Claudine van der Sande, Shanti Thakoerdin, Emmy de Wit, Sebastiaan Blok, Joyce den Besten, Durwin Lynch, Denise van Kampen, Tessa Frankena and Yang Qin.

Thanks are due also to Dave Lupton, who generously allows use of his Crippen cartoons on the internet. We recommend that readers have a look at his site:
http://www.crippencartoons.co.uk

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Finally, we want to thank our own organisations for allowing us to spend time and resources on this project.

Disability, exclusion and inclusion

'Disability need not be an obstacle to success (...) We have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine. It is my hope that (...) this century will mark a turning point for inclusion of people with disabilities in the lives of their societies.' Professor Stephen Hawking

The mystery of the missing and marginalised

People with disabilities are estimated to make up about 15% of the world population. They are often among the most marginalised of the poor. 20% of the world's poorest people have disabilities, according to the World Bank.
(UN Enable, 2009)

→ *People with disabilities don't appear in the development landscape*

In theory, people with disabilities have the same rights as you and me to fully participate in all spheres of life: in family life, at school, in the workplace, in politics or in religious services (UN Convention on the Rights of Persons with Disabilities, 2008). However, the reality in many developing countries is the opposite. Children with disabilities hardly attend school. Adults rarely participate in community activities such as meetings, festivals and religious services. They often have no access to the labour market and encounter serious discrimination in seeking employment or involvement in self-help groups or income-generating activities. Girls and women with disabilities are extremely vulnerable to physical and sexual abuse, particularly when they have an intellectual disability.

→ *Large development agencies spend just 1% of their micro-credit activities on disabled people (SARPV, 2001)*

There is a strong link between disability and poverty. Poor people have a higher risk of acquiring a disability: they do more dangerous jobs, such as working in mines, industry, building and road construction. They are more exposed to disabling diseases and conditions. Poor people often live in conditions that may lead to disabling conditions, for instance with more exposure to violence, fires and so on. They usually eat poor quality or a limited variety of food, which may result in disabling conditions, such as rickets, and they have less money to spend on medical assistance.

At the same time, disabilities increase the possibility of falling into poverty. People with disabilities often lose their jobs or are prevented from participating in school and work. This cycle of disability and poverty must and can be broken. Development agencies should play a vital role in breaking this cycle and creating equal opportunities for persons with disabilities. However, the bitter reality is that persons with disabilities, who often belong to the poorest of

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The Convention came into force in 2008. It specifically calls for development programmes to include people with disabilities.

Article 32 – International cooperation
States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
(c) Facilitating cooperation in research and access to scientific and technical knowledge;
(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

Article 11 - Situations of risk and humanitarian emergencies
State parties shall take, in accordance with their obligations under international law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

- There's a strong link between poverty and disability (World Bank, 2010);
- 75-90% of persons with disabilities in the South live below the poverty line (WHO, 2011);
- there's a strong linkage between low and irregular income and disability (World Health Organisation, 2011);
- forty million of the 115 million children who don't attend school have a disability (EFA Global Monitoring Report, 2010). Thus, one-third of all out-of-school are children with disabilities;
- it is estimated that 50,000 people, including 10,000 disabled people, die every day as a result of extreme poverty (KAR, 2005);
- over 1 billion people live with some form of disability. This corresponds to about 15% of the world's population (WHO, 2011).

the poor, seldom benefit from development programmes. How is it that the people who need them most cannot access poverty alleviation projects? Why do so few development organisations pay attention to this marginalised group in their programmes? Read on. We will try to unravel this mystery.

What is disability?

Ask people what disability is and you will get many different answers and viewpoints. Some people will say disability is a personal tragedy; others see it as a medical problem; and still others will say disability is just a part of life and should be accepted as an aspect of diversity.

It is important to try to understand what disability means to people. Only when we do so will we be able to effectively address the marginalisation of persons with disabilities.

← *Definitions are important!*

→ *Don't confuse 'impairment' with 'disability'*

People often think that this marginalisation is caused by the individual in question's impairment and its consequences for their capacity to function. But, in reality, the attitudes and beliefs that society holds about disability contribute greatly to marginalisation.

Two key concepts that need to be kept separate are impairment and disability. These two terms are often used interchangeably, but the distinction between them is vital to an understanding of the issues. 'Impairment' refers to problems in bodily function and structure as a result of a health condition – for example, blindness or paralysis. 'Disability' has a broader meaning. It refers to impairment, limitations in activities (such as the inability to go to the toilet) and restrictions in participation (such as difficulties in being employed, going to school or making use of public transport).

→→ *'Disability' involves interaction with the environment*

→ *And the environment can be changed*

Disability is much influenced by the interaction between the individual and his or her social, cultural and physical environment. There are plenty of situations in the environment that are disabling and a distinction can be made between those that cannot be changed (for example, high mountains) and those that can be changed (stairs can be changed into a ramp or replaced by an elevator). There are also situations or conditions that may help individuals to be less disabled. For instance, while the mountains cannot be removed, it may be possible to make public transport in the area accessible to people who use a wheelchair, while a ramp or elevator enables people who use a wheelchair to access buildings.

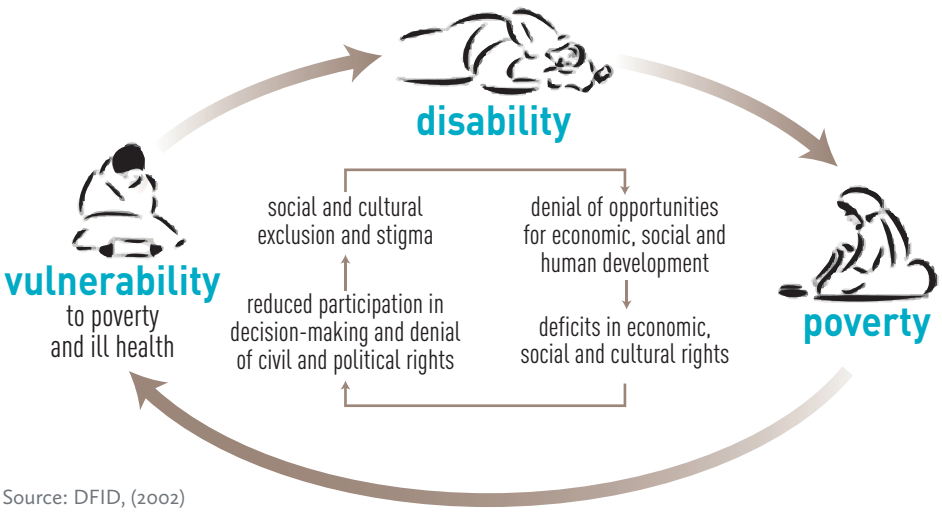
→→ *Barriers can be removed...*

The UN convention on the Rights of Persons with Disabilities (UNCRPD) uses the following definition: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

→→ *...Or they can lead to loss of self-esteem...*

Disability is therefore not simply an attribute of the individual: it is an interaction between the person and his or her environment. Interventions and actions aimed at enabling people with disabilities to participate in all spheres of life must therefore move beyond the traditional concept of rehabilitation and medical treatment. Enabling people to participate in social life can largely be achieved by addressing the barriers that hinder persons with disabilities in their day-to-day lives. These barriers are often found in society.

Sometimes people with disabilities have internal barriers as well that may seriously affect their participation and functioning in society. For instance, it could be that people are not motivated to contribute towards their own development or they may have a lack of self-esteem and believe they are not capable of learning new things.



Source: DFID, (2002)

‘Despite numerous policies and statements regarding disability and poverty reduction, it is still estimated that 50,000 people, including 10,000 disabled people, die every day as a result of extreme poverty. This is not an abstract theory, but a disastrous crisis. It would be deceptive to claim that this injustice is anybody’s conscious intention. However, it can be argued that it is the inevitable and logical result of existing global relations.’

Rebecca Yeo, KAR, 2005

1 Rights based approach,

(from Harris and Enfield, 2003, p.172)

2 Medical approach

(from Harris and Enfield, 2003, p.172

Different approaches to disability

The new rights-based perspective[2] on disability emphasises that persons with disabilities are often prevented from reaching their full potential not because of their impairment, but as a result of legal, attitudinal, architectural, communication and other discriminatory barriers. Persons with disabilities should be recognised and accepted as full and equal members of society who have important contributions to make to their families and communities, and have a right to access all basic needs – including schooling, health services and rehabilitation services. This new approach aims to give people with disabilities access to regular development programmes, rather than organising special programmes exclusively for persons with disabilities.

The new understanding about disability challenges the more traditional viewpoint that disability is a strictly medical problem that needs to be addressed. In this medical approach the only focus is on 'curing' the disabled individuals to fit them into society. The issue of disability is limited to the individual in question: the disabled person has to be changed, not society or the surrounding environment.

According to the medical approach, persons with disabilities need special services, such as special transport systems and welfare social services. For this purpose, special institutions exist: for example, special schools or sheltered employment places where professionals such as social workers, medical professionals, therapists and special education teachers determine and provide special treatment, education and occupations.

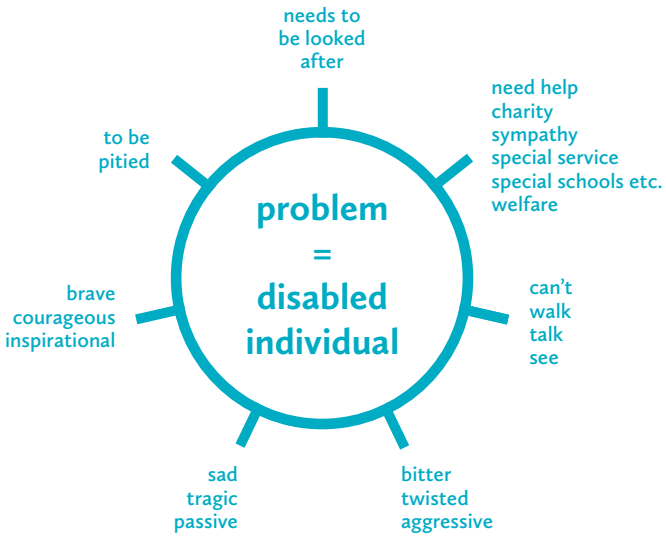
The new rights-based approach also challenges the viewpoint that persons with disabilities should be objects of charity, unable to lead their own lives.

This so-called charity approach sees people with disabilities as victims of their impairment. People with disabilities are to be pitied and need our help, sympathy, charity and welfare in order to be looked after. This old approach solved the problem of disability by creating special schools and special welfare programmes for persons with disabilities. Sometimes people with disabilities themselves adopt this concept, in which case they usually feel 'unable' and have a low sense of self-esteem.

This guide will show what it means for organisations to work from a rights-based perspective on disability. We will explain how the medical and charity approaches, which are deeply rooted in our thinking, can be overcome.

3 Charity approach

(from Harris and Enfield, 2003, p.172)



'As the world strives to achieve the MDGs [Millennium Development Goals], it's important that disability is not treated as a leftover.'

Peter Obeng Asamo, Director, Ghana Association of the Blind

Dave Lipton at www.crippencartoons.co.uk

Why are people with disabilities excluded from development programmes?

'I have almost thirty years of experience in development cooperation and have done many needs assessments, but never realised we missed out on persons with disabilities till now. We never thought of inviting persons with disabilities before.'

Programme manager from an Ethiopian NGO

There are several reasons why persons with disabilities are overlooked in mainstream development programmes. It is not usually a matter of ill will on the part of organisations: development practitioners are simply not aware of the needs and capabilities of persons with disabilities, who are not very visible in society.

People with disabilities often have limited mobility so they stay around the house and do not attend community meetings. They are thus easily overlooked when new projects are starting up and are not invited to raise their voices during project design. The outcome is that their needs are not taken into account in the projects. This may lead, for example, to evacuation plans that

‘We cannot include children with disabilities in our Child Sponsorship Programme because of the criteria of our donor: a child should be able to learn and should be able to walk to school on its own.’

Field staff in an education programme in Ethiopia

do not pay attention to people with limited mobility. Or it could mean that water points are not accessible to people who use wheelchairs. And if programme activities and information are not accessible, it is difficult for persons with disabilities to participate.

There are three main categories of barriers that prevent persons with disabilities from participation: attitudinal, environmental and institutional.

Attitudinal barriers

Prejudice, shame and discrimination cause the biggest problems for persons with disabilities, who are often assumed to be incapable, dependent, of low intelligence and in need of a cure or special services and support. Contradictorily, they are sometimes viewed as

Common excuses for not including persons with disabilities

- **Including persons with disabilities is too costly.**
- **We don't have the knowledge to do it.**
- **Persons with disabilities need special programmes.**
- **Why should we invest in people who cannot perform? Let us sort out the problems of 'normal' people first.**
- **There aren't many disabled people here, so it is not an issue.**
- **We don't do disability.**
- **We are overloaded; we don't have time for an additional issue.**
- **Our donors are not interested.**

inspirational, exceptional and heroic if they are able to live independent lives. The latter is in itself not a problem; however, it can easily take the form of caricature.

→ *Prejudice, shame, discrimination*

Non-disabled people can respond with fear, pity and aversion, or with a sense of superiority. The media often reinforces these assumptions and emotions. Additionally, negative language – 'victim', 'leper', 'crippled' – reflects and reinforces prejudices.

→→ *Communication barriers*

It is not only the community who might think that persons with disabilities are not able to take care of themselves. Project staff might also have this attitude. It's very common. Here's what field staff of an income-generating programme in Bangladesh said:

'During our identifications we found some elderly women and women with disabilities, but we could not enrol them in the programme because they were not able to learn and not able to work.'

Environmental barriers

There are many physical barriers that prevent persons with disabilities from participation. Public transport, health clinics, schools, offices, shops, marketplaces and places of worship are often not accessible to persons with physical

disabilities. Communication, media and information can contain barriers for persons with speech, hearing or visual impairments if the information is not presented in an accessible format, such as Braille and large-letter type for people with visual disabilities or the use of sign language for people with communication disorders. As Dilkamo, the father of an Ethiopian child with a visual impairment, explained to researchers:

'I do not send my child to school because the school is not accessible. I have tried to send my child but she came back crying. She asked me why I was doing this to her as she could not see and learn anything in the class. Also the other children were bullying her. So I keep her at home now.'

Institutional barriers

There are also institutional barriers that prevent persons with disabilities from participating in domains such as politics, religious services and employment. Examples of such barriers are discriminating legislation, employment laws and electoral systems. Often, they do not accommodate the needs of blind or intellectually disabled people.

Exclusion can also be based on belief systems that regard impairment as a result of sins committed in this or in past lives. There are also discriminating policies within humanitarian and development agencies. During this Thematic Learning Programme, an organisation in India realised that their school admission criteria – which included the caveats that children should be able to walk to school unaided and that children should be able to learn – were excluding children with disabilities.

Additionally, many micro-credit programmes see disabled people as a high-risk group since they believe that they are less productive and less capable of running a viable business. Some vocational training programmes use the criteria that trainees should be able-bodied and fit to work and thus exclude persons with disabilities because they are not considered fit enough to work.

Dave Lipton at www.crippencartoons.co.uk

↔ *Discriminating legislation*

Excuses

Development organisations often have many excuses why they are not actively including persons with disabilities. Even the organisations that joined this Thematic Learning Programme struggled with these issues. Throughout this publication we will try to demystify the excuses and give advice on how to overcome resistance within organisations. A big part of the resistance can be taken away if we are able to grasp what disability-inclusive development means and what role mainstream development organisations have.

↔ *Belief systems*

What is disability-inclusive development?

→ *Including people with disabilities is often more efficient and effective*

By including persons with disabilities in regular development programmes you make a very important public statement: you accept people with disabilities and view them as equal members of society. This is the only way to ensure that people with disabilities get access to basic services and can get out of poverty.
The costs of including people with disabilities is often used as an argument against adapting development programmes so they are included. But the reality is that including people with disabilities in mainstream development is more effective and efficient than excluding them.

→→ *People with disabilities have the same needs as everyone else*

Take, for example, segregated special schools for children with disabilities. Without downplaying their importance – since some children definitely benefit from this type of education – there is ample evidence that special educational programmes for children with disabilities are very expensive and only available for the lucky few. And special education reinforces further segregation and exclusion.

It is important for development agencies to realise that people with disabilities share most basic needs with other people in society. Everyone is, for instance, in need of drinking

Inclusive development stands for

- **Equal rights** The entire community, including persons with disabilities benefit equally from mainstream development processes. Disability-inclusive development sets out to achieve equal rights for people with disabilities as well as full/active participation in, and access to, all aspects of society.
- **Participation** Persons with disabilities participate in all benefits of mainstream programmes and thus also participate in decision-making.
- **Accessibility** Environmental, institutional and attitudinal barriers are identified and addressed to ensure that people with disabilities are fully included in all spheres of life, that they participate in society and are optimally able to achieve their ambitions.
- **Sustainability** Inclusive development is not a one-off activity. Including persons with disabilities needs to be embedded in all the veins of the organisational culture. This will become visible in the organisations' policies, systems and practices.

water and sanitation facilities. Everyone needs mobility, although an able-bodied person may have more options to satisfy that need than a person with a mobility limitation. Everyone needs social interaction. All need to belong to a family, household and society. All need to find meaning in their lives and to fulfil their dreams. Although children and adults with disabilities may have special needs, most of their needs are shared with everyone else. As the World Health Organisation puts it:

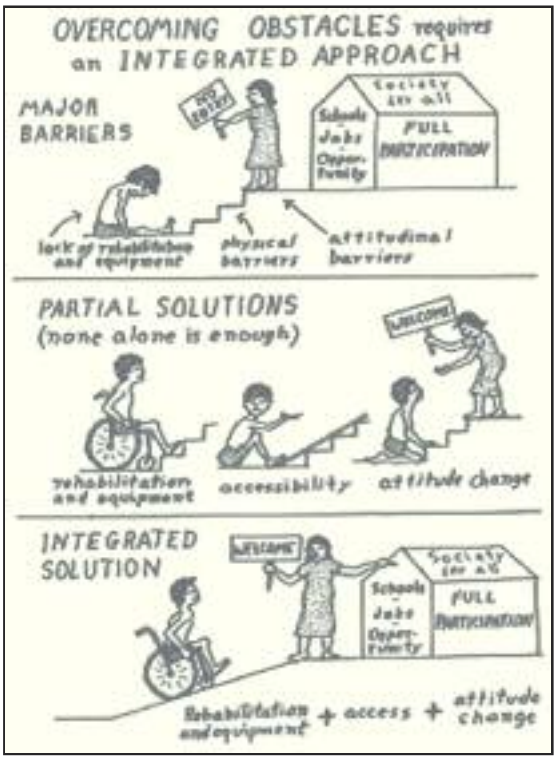
'People with disabilities have ordinary needs – for health and well-being, for economic and social security, to learn and develop skills, and to live in their communities. These needs can and should be met in mainstream programmes and services.'

Consequently, meeting the needs of everyone in mainstream development programmes, including the needs of people with disabilities, is often most appropriate and efficient. Very simple adaptations to existing infrastructures such as playgrounds or school buildings – through, for instance, ramps and wider doors or simply ensuring classrooms are on the ground floor for children using wheelchairs – may be enough to allow all local children to get schooling. Similarly, simple and cheap adaptations can often be made to computers, water pumps, public transport and so on.

Of course, children and adults with disabilities may have special needs that require special services. They may be in need of special equipment or appliances such as a wheelchair or prosthesis. Such provisions should be made available through specialised services, which exist in most countries nowadays. These specialist services can be found within the public or private sector and don't need to be expensive. Often, low-tech solutions are available within so-called community-based rehabilitation programmes. In such programmes, special seating and equipment is made of low-cost materials.

← *Simple, cheap adjustments are often all that is necessary*

The role of mainstream organisations in inclusive development



Werner, D. (1999). Disabled Village Children. Hesperian Foundation

→→ *Just remove the barriers*

Realising the full participation of people with disabilities in society cannot be achieved by mainstream organisations alone. It is the responsibility of all: government, community, disabled people and their organisations, development and humanitarian agencies as well as disability-specific organisations or service providers. It is the role of mainstream organisations to open up their programmes for persons with disabilities, to remove the barriers and to make the services accessible. Nothing more, nothing less.

→→ *80% of persons with disabilities do not need specific interventions*

80% of persons with disabilities can participate in social life without any specific additional intervention or with low-cost and simple community-based interventions that do not require any specific rehabilitation expertise.[3]

The other 20% of persons with disabilities – those who cannot actively participate in, and benefit from, mainstream development programmes without specific measures that

need to be taken (for example, providing a prosthesis or a wheelchair, physiotherapy or surgery) – can and should be referred to disability-specific organisations such as orthopaedic workshops, physiotherapy services and special-needs educational institutions. These specific service providers can deliver the necessary interventions and equipment or make the necessary adaptations.

There may be people who cannot be involved in mainstream programmes and we should be aware of this as well. It would be difficult or impossible to include, for instance, severely intellectually disabled children and adults in local schools or at the workplace. It may be that in the cases of severe physical disabilities – for example, being bedridden because of complete paralysis – family members can be included in our programmes. In addition, we should refer such cases to a disability-specific organisation or service.

This way of working is called the twin-track approach. Persons with disabilities should be included in regular programmes where possible and should also be able to access special services when this is really needed. This means, in the case of education, for instance, that children with disabilities should be included in the existing mainstream and public education system to the maximum extent, and special services should be made available only where inclusion in the mainstream is not possible – for example, in the case of children with multiple disabilities.

In the Building networks chapter you will find more information about the role of different stakeholders in disability-inclusive development.

↑ *Include family members in programmes*

↑ *The twin-track approach*

[21

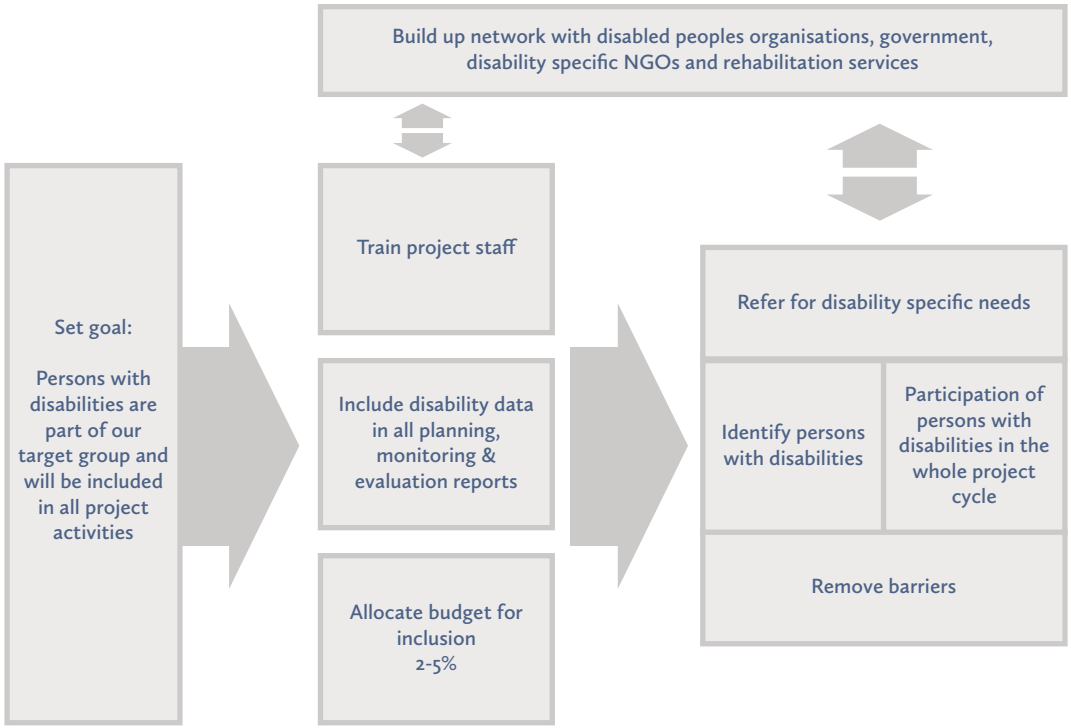
Creating disability-inclusive development programmes

'I work at a hotel to organise their bookings. At first my employer was a bit doubtful about buying JAWS (software for blind computer users) for me, but now they are happy with my skills and dedication. They are planning to hire more persons with visual impairments at the booking department and I will become their trainer. Most important to me is that I made many friends and I am finally able to support my parents and younger brother. I am even thinking about the possibilities of marriage!' **Shankar**, former client of an LCD livelihood resource centre, Bangalore, India

Steps in making programmes inclusive

Including persons with disabilities in regular programmes does not require many extra activities. The basic idea is that when new programmes are designed, you deliberately involve people with disabilities at all stages of the project cycle, from stakeholder analysis to needs assessment and definition of project activities. The figure on the next page shows the different steps involved in designing a disability-inclusive project.

Rahila received chickens and now makes a living selling eggs



The first step is to make a commitment. People with disabilities are part of your target group and you want to include them in all project activities. This statement will put everything in motion. You should also allocate a budget for inclusion and include disability data in all planning, monitoring and evaluation reports.

A crucial step is the training of project staff. They need to be made aware of the rights, needs and capabilities of persons with disabilities. They will then be able to start identifying such persons to be enrolled in new or existing projects. Once identified, the people with disabilities should be empowered to participate in the whole project cycle: planning, implementation and evaluation. To ensure successful participation, they should also have access to medical or rehabilitation care. Not all of them will need this care, or devices such as wheelchairs, but it is crucial to the quality of their inclusion process. Mainstream organisations should refer persons with disabilities to other service providers to meet these disability-specific needs.

Probably the most important step in the inclusion process is the removal of attitudinal, environmental and institutional barriers that prevent participation. Then there is the building of networks with disability-specific service providers, disabled people's organisations and governments. They can help your organisation in many ways.

In the following pages each of these steps will be described in more detail and illustrated with real-life examples, dilemmas and solutions.

← *Remove barriers*

←← *Involve people with disabilities at every stage*

←← *Train project staff on the rights, needs and capabilities of disabled people*

Training of project staff

→ *Staff sensitisation is essential*

Persons with disabilities are not included in projects because project staff is often not aware of the needs and rights of persons with disabilities. It is not a sign of ill will; it is just a matter of overlooking a group of people who are not very visible in society. Once we are aware of the needs and capabilities of persons with disabilities, it becomes easy to open up the projects and remove the barriers. Motivated field staff is a key priority when working on inclusion. They are the ones to discuss the topic with communities and identify new project beneficiaries. So staff sensitisation on the rights and capabilities of persons with disabilities is one of the first steps to take.

→ *Discuss stigmas attached to people with disabilities*

During the Thematic Learning Programme, managers faced the big issue of how to organise a good training programme. What kind of knowledge, attitude and skills does project staff need? Do they need medical knowledge to identify persons with disabilities? Or extensive training in rehabilitation? We came up with the following answers.

Attitude change

→ *Challenge the stereotypes*

The first step is to challenge the stereotypes that exist about persons with disabilities. We all have certain images and ideas in our minds about such persons: they need help, they can't learn, they need special services and so on. But are these ideas correct? Did we ever check?

Elements of staff training

- Discuss local beliefs, prejudices and culture related to disability.
- Introduce appropriate terms to refer to persons with disabilities.
- Explain the rights of persons with disabilities to participate in all spheres of life.
- Identify the barriers for persons with disabilities in the project.

In our training, we always explain the different approaches to disability and say we want to work from a rights-based approach and not from a charity or medical perspective (see Part one). At the end of the session, project staff should be able to look at persons with disabilities as full members of society who have ordinary needs and rights. The stigma related to disability can be very strong in some cultures and communities, so this really needs to be discussed and analysed during staff training.

Travelling Together is a one-day training course that guides international development workers through a simple process of radical change. The training guide offers a set of very practical and tested exercises that can be used for staff training.

http://www.worldvision.org.uk/our-work/reports-papers-and-briefings/travelling-together/

Blind bicycle repairman in Bangladesh

'When we organised a training programme,' recalls a church leader in Ethiopia, 'we asked one of the church members, a famous blind singer, to give a lecture on disability and theology. He delivered a very impressive speech explaining that some important biblical persons had disabilities: Moses stuttered, Paul was blind for some days. The impact of this speech was enormous. It really touched people's hearts. During the final prayer, the participants asked for forgiveness for the discrimination they had exercised towards persons with disabilities in the past. We strongly believe that these church leaders will do their uttermost to include persons with disabilities from now on.'

← *Involve disabled people in staff training*

Knowledge and skills

→ *Staff need to learn how to remove barriers*

Not much knowledge is needed to start including persons with disabilities in mainstream programmes. The role of project staff is to find persons with disabilities in the project area and make sure that they are included. To do this, they must understand what disability is and the different kinds of impairment that exist. They should also understand how they can remove the barriers for persons with disabilities and what kind of adjustments need to be made to include them. For example, what does a hearing-impaired child need to be able to participate in school? Or how can the local health clinic be made accessible to persons using a wheelchair?

→ *They must have in-depth knowledge of services that are available*

Project staff is not responsible for diagnosis, medical rehabilitation or for the measurement for and distribution of medical aids, so they don't need extensive medical knowledge. For these kinds of services they should refer the person in question to disability-specific service providers. However, knowledge of local disability laws, schedules, programmes and services is very useful. This will help project staff to refer persons with disabilities to the appropriate facilities to have their disability-specific needs met.

What we have learned about training field staff

→ *Organise a visit to a successful inclusive project*

During the TLP, many organisations in India and Ethiopia organised training sessions for their field staff. What can we learn from these experiences?

→→ *Let disabled people explain their own needs, wishes and abilities*

Seeing is believing! When project staff is exposed for the first time to the topic of inclusion of persons with disabilities, they often have serious doubts about the capabilities of such persons. Are they really able to participate in a regular programme? How can a blind man be successful in farming? How can a paralysed woman ever run her own shop? How can a deaf child learn to read and write? There's a big chance that they don't know anybody with a disability who is able to earn their own income.

So it is really important to show them how persons with disabilities can be included in a regular project. You could organise a visit to a successful disability-inclusive project in your working area. Or invite a person with a disability who is earning their own income and participating fully in community life. Personal real-life stories are the best way to bring the message across. If you can't organise a personal testimony, you can also use case stories, movies, videos and photos. There are plenty of resources available on the web.

http://www.endthecycle.org.au/content/the-people-experience-their-stories/all-stories/

Involve people with disabilities as trainers

The best advocates for the rights of persons with disabilities are disabled people themselves. Invite a disabled people's organisation to provide training on disability rights and inclusion, or hire a trainer with a disability. In many countries, there are centres for disability and development. They have qualified trainers and are able to design tailor-made training courses for your organisation.

Their involvement will also make you aware of needs you may have for changes!

'*When Shitaye, from the Ethiopian Center for Disability in Development, came to us to do the intake assessment, the inaccessibility of our office became very clear,' confesses the manager of a WASH programme in Ethiopia. ' She could not enter with her wheelchair, so we had a meeting in our parking lot. This really shocked me. I felt very sorry about that. This was a huge motivator for me to really change something.*'

Take away the uneasiness

People sometimes get very nervous when they come across a person with a disability. 'Help, this guy is blind! What to do? I don't even know how to shake hands with him. Will he get angry if I say, "It's good to see you"?'

The best way to overcome these fears is by direct interaction with persons with disabilities. Let people share their fears and doubts in a non-threatening atmosphere and have a good laugh together. During a training activity, you can ask participants to write down a question about disability on a piece of paper. It should be something they always wanted to know, but never dared to ask a person with a disability. Put the questions in a box. Pick out some of the questions and let them be answered by one of the trainers with a disability.

During one of our training sessions the following questions came up:

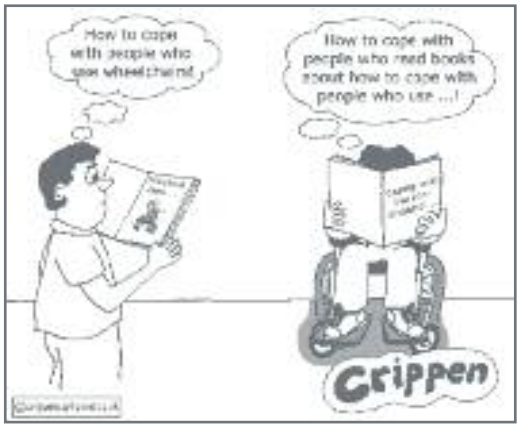
How does a blind person fall in love?

Yetnebersh: 'Many sighted people believe that love is dependent on being able to see, but love is not about colour or visual image. Love is getting familiar with someone. You choose to stick to his or her special quality. A blind person may have their own experience of beauty; it is not dependent on vision. We smell, test, touch and listen to things and we also develop our own way of coping with things that we do not see. Also a close friend can help a blind person to imagine how their loved one looks.'

When did you first realise that you had a disability?

Yetnebersh: 'I realised that I was disabled when others were told to collect harvests from the field and I was to sit at home. Because I am blind.'

Pande: 'I got a (partial) visual impairment when I was four years old. However, until I reached the age of 14, I had not realised that I had a disability because I was part of an inclusive environment in school, at home, outside, with friends and so on. Later, when I was studying in the ninth standard, I started facing a lot of barriers/difficulties such as reading, writing, travelling, making friends, going out and so on, as my vision deteriorated with time. It was then I realised that I had an impairment. I realised later that nobody is abled, because everybody has some sort of disability. With this thought in mind, I moved ahead with a feeling that I was no different and capable of doing everything like everyone... This helped me to cope with my Impairment.'



Dave Lipton at www.crippencartoons.co.uk

↢↢ *Direct interaction with people with disabilities removes the fear and uneasiness*

↢ *'Nobody is abled, because everybody has some sort of disability'*

Tips for interacting with persons with disabilities

- Speak directly to the person with the disability and not to his or her interpreter or assistant.
- Talk in the same way as you speak with anybody else; speak clearly and do not shout or mumble.
- Never treat an adult or elderly person like a child.
- Make sure when communicating with people with disabilities that you are at the same eye level. This is the best way to show that your attention is directed to him or her and you are paying heed to what he or she is saying.
- Offer assistance if you feel that this may be needed, but never help someone without asking whether he/she wants assistance. If you assist someone, ask how they want you to help them.
- Do not stare if someone or something about the person seems unusual to you, but don't shy away from people who have a very unusual appearance.
- Talk about people by mentioning their name and do not refer to them by mentioning their impairment.
- Treat the person as you would treat anyone else and as you would like to be treated by others.

Identifying people with disabilities

→ *Some disabilities are not visible*

You frequently hear it said that it is difficult to find people with disabilities. Some of them, especially children, who have severe disabilities are hidden or don't come out of the house very often. Moreover, a number of disabilities are not visible: for example, people with communication disorders and people who are partially sighted. How then can we identify people with disabilities?

→ *Include disability in your baseline study*

The first step is a recognition that people with disabilities live in every society. They are there; you just need to find them. One of your next moves could be to gather disability data from your project area. There may be government statistics available. Otherwise local disabled people's organisations or disability-specific organisations will be able to tell you more about the prevalence of disability in your area. The most important thing is that you get an idea of the magnitude of disability.

→→ *Collect the data*

If you are setting up a new programme, disability should be included in the baseline study. We strongly advise you not to rely on numbers and/or percentages only. All too easily, you may think the 'problem' is either too small or too big to deal with. The question, however, cannot simply be narrowed down to numbers or percentages. The question is, 'How best can our organisation include people with disabilities in our programmes?'

Another important step is to ask ourselves the question, 'How many adults and/or children with disabilities and how many carers/family members already benefit from our programmes?' If such data is not yet collected in your projects, this is a good moment to start doing so. [

→→ *Let disabled people help you identify others*

Fieldworkers are often able to produce a list of people with disabilities who are already enrolled in the programmes, but it requires more effort to find out whether project beneficiaries have disabled household members. This question could be asked during one of the project meetings. It is advisable to note down age, gender and kind of disability. When you know if, and how many, people with disabilities are already included in your existing programmes you need to make efforts to find and include other disabled people as well.

You will be surprised how easy it is to find people with disabilities when you start inviting them to join your programme. Often, they can best do the identification of other disabled people themselves, since they usually know other people with disabilities. Over the course of the years, more and more people with disabilities will show up when they see that others are participating. The power of role models is of vital importance in achieving more inclusive development.

How to find persons with a disability in your project area

- Include disability data in baselines studies for new projects.
- Identify persons with disabilities who are already enrolled in your programmes.
- Link up with local disability-specific organisations or disabled people's organisations and ask them for names and addresses.
- Use existing data from the government or from disability NGOs in your area.
- Talk with community and religious leaders. Explain you want to include persons with disabilities in your programmes. Most likely they will be willing to show you the homes of people with a disability.
- Organise a meeting with people with disabilities and ask them for advice on how to find other disabled people.
- Organise a disability awareness session in the community and ask the participants to help you find persons with disabilities to be enrolled in your programme.
- In the case of childhood disability you can ask children from the programme you support or run (for example, schools or clubs) to identify those children who are not participating.

People with disabilities must participate in the whole project cycle

→ *Not used to being listened to*

It is commonly recognised that the development of a community development programme without the participation of the target group is a recipe for failure. Developing a disability-inclusive programme without participation of people with disabilities will also fail. In general, people with a disability belong to the most marginalised groups in society and are not used to being heard and listened to.This is an additional challenge, as people with disabilities often lack education, have not been involved in public gatherings and meetings, and consequently often lack self-esteem. Some people with disabilities are, however, vocal and outspoken. It is tempting to ask for their opinion but beware: those may be the people who have been able to go to school. Those may be the ones who acquired a disability at a later age. Asking for their opinion may give you a skewed picture of the reality.

→→ *Often they lack education*

You should also make sure that people with a disability participate in the entire process of planning and development. There is ample

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evidence that focus group discussions with (representatives) of people with disabilities are an effective way to get the views of people with disabilities. If you decide to use this strategy, you should make sure that different disability groups are equally represented and you may need to organise focus group discussions for various interest groups such as women, men and children.

A meeting that includes people with disabilities or a focus group of people with disabilities needs careful facilitation. Invite them personally or through community leaders, religious leaders, community or family members or through local disabled people's organisations and disability programmes. This could be the first time that people with disabilities are recognised as potential beneficiaries of mainstream programmes or are being asked to voice their opinions, concerns and needs. They may produce a personal wish list (for example, food, housing, money, clothes) and at first may not be able to perceive the importance of representing their peers. They have often grown up with charity. It is your task to interpret the personal wish lists in such a way that you are able to synthesise those items into commonly felt needs that can be addressed by or through your programme.

Focus group discussions can be useful

Careful facilitation needed

How to involve persons with disabilities in the planning process?

- In the situational analysis of communities, always pay attention to disability.
- Always include representatives of people with disabilities in the planning committee.
- Organise special focus group discussions with people with a disability.
- Make sure that various groups of people with disabilities are consulted

→ *They often know the solutions themselves!*

People with disabilities can perfectly identify the barriers they face in society and the reasons why they are excluded. Women with disabilities can inform you about the double discrimination they face in the family and in society. Most often, people who inform you about the barriers they face are also able to give you the solutions that are needed to remove those barriers.

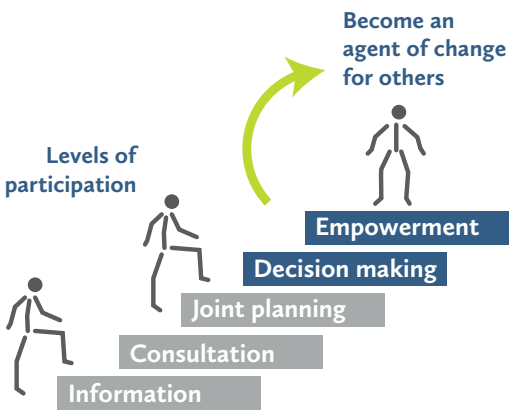
→→ *The aim should be for them to sit in the driver's seat and become role models for others*

There are different levels of participation in projects. It starts with information sharing. This is a limited form of participation, where persons with disabilities are simply informed about decisions, but it at least recognises their existence in society. When we ask input of people with disabilities during the planning and development of our programmes and provide them with the necessary feedback, we listen to them. This kind of consultation does not ensure that their opinions are taken into consideration. Meaningful participation gives people with disabilities the right to negotiate during the planning process, as well as during the implementation and follow-up of the activities. Such participation takes place at the interface of joint planning and joint decision-making.

→→ *Meaningful participation gives them the right to negotiate during the planning process and afterwards*

Where possible, we should develop strategies and activities to intentionally include people with disabilities in the entire process of planning, monitoring and evaluating the programme and its activities. Finally, and ideally, we should try to reach a situation whereby persons with disabilities are enabled to sit in the driver's seat as well. If that takes place, they will become role models for others and they will function as agents of change. Real empowerment will be the result.

Levels of participation



Good practices

Yasmin

Yasmin & Rahila

Yasmin is a young woman living in the Gaibandha district in Bangladesh. She was so happy when she found a husband because it's not easy for a visually-impaired woman to get married. But the love didn't last long. After a month her husband left her. This was disastrous because when her man was gone Yasmin found out that she was pregnant. During her pregnancy she could still work as a maidservant, but when her son, Rubel, was born she couldn't go out to work. Luckily, she was invited to join a food-security programme run by ICCO Netherlands that focuses on women-headed households and pays special attention to inclusion of women with disabilities. In the women's group Yasmin is learning how to start her own vegetable garden. She also received seven chickens and she might get a goat later on.

Rahila is participating in one of ICCO Netherlands' other women's groups. She has a hearing impairment. With facial expressions and gestures, she explains that she also received chickens. She is doing a good job. She makes a living from selling the eggs. Yasmin and Rahila are just two of the 40,000 women benefitting from these programmes.

Cartjik gets on-the-job training

Blind man sets up farm in Ethiopia

Facilitators of the MKC-RDA Self-Help Groups received training in disability mainstreaming and started to bring up the issue in their groups. Awareness was raised about the medical causes of disabilities – creating a counterpoint to the religious beliefs and attitudes that had shaped behaviour towards people who were disabled. The aim of these discussions was to reduce the shame about people with disabilities and get them out of their hiding places into the community.

In addition, people with disabilities were motivated to join the Self-Help Groups themselves and their numbers within the groups rose. Awareness about causes of disabilities other than curses and demonic spirits was raised.

Some members with disabilities became successful in business. One blind man, for instance, set up a farm and is now successfully selling considerable amounts of crops that are said to be of a very high quality. The successful members with disabilities are now used as role models to inspire and motivate others to join the Self-Help Groups.

Cartjik gets job training

Cartjik is 18 years old. He joined the after-school support centre of WORD Trust two and a half years ago. Though he has an intellectual disability he learned to manage his own affairs at the centre. He is independent in self-grooming now and he can perform tasks without support. He has become independent in all daily activities: to meet us, he especially put some bracelets and a ring on.

Now, he's following an on-the-job training programme to become a painter. With the money he earns, he would like to buy a vehicle and to build a house for his family. His mother: 'He is important for us, whatever he asks we try to provide.' To complete her dream she has

bought some land for her family and is preparing her other son to take care of Cartjik in the future. Due to the intervention of WORD Trust, she is now able to save some money every month and her family is enrolled in an insurance scheme.

Kids raise awareness

Ethiopian Kale Heywet Church (EKHC) introduced disability clubs in its schools in Ethiopia. The children, both with and without disabilities, form clubs and start to raise awareness in their families. They ask the parents to bring their children with disabilities to the schools. Teachers also try to address the issue in the community and on parent's days they hold public meetings, debates on disability and exchange views and ideas.

Kids can learn respect for people with disabilities

Wabe Children Aid and Training (WCAT) trained children in Ethiopian schools to use correct terms to address their classmates with disabilities. The children teach each other after the training and correct each other. If somebody says, 'Oh, the blind person is coming,' the other will say, 'No, you cannot say "blind person". You should call her by her name.'

Making disabled people feel welcome

Emmanuel Hospital Organisation in India wanted to show that persons with disabilities were welcome in their hospitals and programmes. So, on World Disability Day, 1 December, they organised a celebration and asked the Village Health Volunteers to bring flowers for persons with disabilities. The people who joined the meeting said they had never received such a welcome before.

Disabled women earn own incomes

In a food security programme in rural Bangladesh, women with disabilities are enrolled in women's groups right from the beginning of the project. All groups receive training regarding disability: what is disability, how to recognise it, what can you do to prevent disabilities amongst your children, where to go for treatment, what are the government provisions for persons with a disability. And last but not least they learn how to treat their disabled group members with respect.

It is a great experience for the disabled women to be enrolled in the group. For some, it is the first time they are addressed by their names instead of being called 'that deaf woman' or 'the crippled one'.

The women with disabilities participate in the income-generating activities and are able to generate their own incomes just like all the other women in the groups.

Awareness raising leads to requests for aids

EKHC's water and sanitation programme in Ethiopia started to include persons with disabilities. They raised awareness in the community about disabilities, and people with disabilities were eventually elected to be members of village water committees. A disabled man was appointed supervisor of one of the water points. But the effect of the awareness-raising was also that people with disabilities started asking for wheelchairs and medical treatment. As a water and sanitation programme, they were not in a position to deal with these requests so they linked up with disability service providers to refer persons with disabilities for assistive devices and medical treatment.

Blind man sees the solution himself

EKHC's Water and Sanitation programme supported the building of a public toilet in a rural village. The organisation consulted people with disabilities. A blind man needed someone to bring him to the toilet. By putting a rope along the road to the toilet he is now able to go to the toilet by himself. The idea of the rope came from the blind man himself.

When a disability expert heard about this solution, he suggested that the man could benefit from orientation and mobility training. Then he can learn to walk with a stick and he can find the toilet without a rope.

Include disability data in all planning, monitoring and evaluation reports

If you aim to include persons with disabilities in your programme, you should start by including disability data in all planning, monitoring and evaluation reports. In this section we explain how to do this.

It starts with including disability data in proposed baseline studies. For a baseline survey, a short set of six questions has been developed, tested and validated by the Washington Group.

If you do a baseline study, for example as part of a situational analysis, you should include disability information and ask also for age, gender and type of disability.

Defining objectives, indicators and targets

We need to develop indicators that will help us to determine how far we are achieving our objectives and our ultimate goal of inclusion for all. If we do not include some specific disability indicators and targets in our plan and (existing) monitoring and evaluation system, we will not be able to measure if people with disabilities access our services or are part of our programmes. But what kind of indicators are needed? We suggest that you start simple. First make sure that you gather disability disaggregated data. This means that if you have a food-security programme, measure how many men and how many women with disabilities are participating in your programme, as well as how

← *Gather disaggregated data*

← *We must be able to measure whether we are making a difference to the lives of people with disabilities*

many households with a disabled family member are benefitting from the programme. It works the same as with gender: simply add disability to each existing indicator.

→ *Resources are available*

CBM, an international disability organisation, has developed five sets of disability sensitive indicators for the education, health, HIV/AIDS, urban development and water and sanitation sectors: http://www.inclusive-development.org/cbmtools/part3/index.htm.

Of course there is also a need for more specific indicators to measure the outcome and quality of the inclusion process. You could use the indicators developed by CBM as an example. The following general questions may also be important depending on the type of activity/programme you execute:

- How do people with a disability perform and participate in comparison to non-disabled participants?
- Why is there a difference?
- Is earmarked budget being used for disability inclusion? Monitor if and for what purpose it is being used.
- How does the partnership/collaboration with DPOs, government and disability-specific organisations develop?

Census questions on disability endorsed by the Washington Group

Introductory phrase:
These questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

3. Do you have difficulty walking or climbing steps?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

4. Do you have difficulty remembering or concentrating?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
a. No – no difficulty
b. Yes – some difficulty
c. Yes – a lot of difficulty
d. Cannot do at all

Sectoral disability-inclusive indicators

Inclusive education
- Disabled children enrolled in regular schools
- Classrooms and toilets made accessible
- Teachers trained in inclusive practices (for example, training in Braille, in sign language, in disability awareness and so on)
- Literacy level of children with disabilities

Inclusive HIV and AIDS interventions
- Disabled people attending and participating in HIV/AIDS awareness meetings and able to access the same information as non-disabled people
- Disabled people accessing the same services and programmes on HIV (counselling, testing and ART) as non-disabled people

Food and water security
- Disabled people have access to sufficient safe water at home and increased access to nutritious food throughout the year
- All new facilities (toilets, wells and so on) that are constructed are accessible to disabled people
- Livelihoods and productivity initiatives are inclusive of disabled people

Child protection
- Combating violence against children and countering power abuse addresses the rights, needs and issues of disabled children
- Community campaigns against violence and abuse of children includes information about the rights, needs and issues of disabled children

Vocational training centres
- The building is accessible to people with mobility problems
- Minimum 5% of the participants have a disability
- Accessible communication formats (such as Braille and audio tapes) are available for people with visual or hearing impairments

Disabled children should be educated at regular schools

Budgeting for inclusion

Inclusion of persons with disabilities in your mainstream programmes does cost money. It is not clear how much inclusive approaches cost because reliable numbers are not available. Major stakeholders, such as Mobility International, advise a budget allocation of 2-7% for including people with disabilities. This is to cover the costs of the following:
- Raising awareness on disability amongst own staff and communities
- Making buildings accessible
- Providing sign language interpretation
- Providing information in different communication formats (Braille, audio)
- Transportation for people with disabilities
- Assistive devices (usually this should be provided by government or disability services; if they are not available it could be paid for by your project budget)

More information about budgeting for inclusion can be found in Part 3.

← *A budget allocation of 2-7% for including people with disabilities is recommended*

Examples of evaluation questions

- Were people with disabilities able to access the full range of services provided?
- What are the achievements of people with disabilities in the project? Do they achieve the same results? If not, what causes the differences?
- What were the difficulties people with disabilities experienced in accessing services or the programme?
- How has the understanding of disability influenced the way your staff is working with people with disabilities? How has this changed in the community? What were the activities that contributed most to this change?
- Did the project alter power relations and has this been in favour of more influence and involvement of people with disabilities in your activities?
- Has the organisational capacity of people with disabilities been enhanced?
- What are the recommendations for improving inclusion?
- Did people with disabilities have the choice and opportunity to become active participants in decision-making processes?
- What types of disabilities are represented?
- What partnerships with disability-specific-programmes/services have been established?
- How are project priorities set and by whom?

Evaluation

The evaluation of your programme offers the chance to measure the outcome and impact of the inclusion of persons with disabilities. But you can also look at the process of change within your project; specifically, the removal of barriers and change in attitude amongst staff and community. Make sure that the voices of persons with disabilities and/or their family members are heard during evaluations.

Monitoring and evaluation (M&E) is supposed to provide critical information and enable policy-makers and managers to make informed and therefore better decisions. Good M&E systems will also help in promoting greater transparency and accountability within organisations and in relation to the general public. As such, organisations – if they provide positive results – will be empowered to garner greater political and public support. The importance of this type of support should not be underestimated. Evidence that our programmes and activities are forming an effective strategy to work towards a more inclusive society is not only needed for accountability reasons, but will form a catalyst in the furtherance of more justice, more equality of opportunity and a world that is better for all.

←
The voices of persons with disabilities and/or their family members must be heard during evaluations

Learning Braille in Nepal

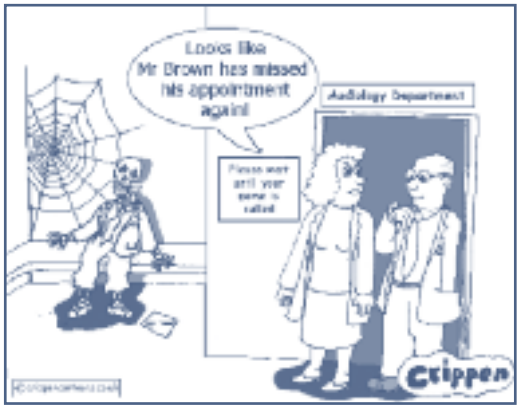
Referral for disability-specific needs

After project staff has identified people with disabilities, what should happen next? Is it possible to immediately include them in existing programmes? Or should there be an intermediary step?

Persons with disabilities are not used to being enrolled in mainstream development programmes, we have learned. A bit more attention is needed here. In India, some disabled people and their families had become so used to receiving charity –money, food, clothes – that, initially, they were not happy at being invited to enrol in a programme to earn their own income. This was something completely new to them.

Often, people with disabilities have low self-esteem and need to be convinced that they can learn and earn their own income. Sometimes parents also need to be convinced that it is a good investment to send their disabled children to school. So, after identification, a few home visits are usually needed before persons with disabilities can be enrolled in a mainstream programme. Then, the needs and wishes of the persons with disabilities and their family members can be ascertained. What do they want? What are their dreams? What are their worries? You can explain how they can benefit from your organisation's projects.

Last but not least, it is crucial that persons with disabilities have access to medical services and rehabilitation care. Very often, disabling conditions are treatable. Many elderly people are blind due to cataracts and a simple operation can restore their sight. The story of Natnaël below shows how important it is that people have access to medical care. Often, people can benefit greatly from physiotherapy or devices such as crutches and wheelchairs. More information about referral to disability-specific service providers can be found in the chapter Building networks.



Dave Lipton at www.crippencartoons.co.uk

↢↢ *Sometimes people with disabilities need to learn that they can earn their own income*

↢ *Often, disabling conditions are treatable...*

↢ *...Or people can benefit from devices such as wheelchairs*

Natnaël's hearing had never been tested

Natnaël's Story

Eight-year-old Natnaël lives in Bahirdar, Ethiopia. His father died some years ago. His mother has heart problems and spends most of her days in bed. Natnaël himself has hearing problems. For nearly two years he has been attending school with his friends. With the support of WCAT, who included him in their Orphans and Vulnerable Child support programme, it has been possible for Natnaël to continue in his class. He is performing well, is a middling student and catches up easily in class. His teacher takes account of his hearing difficulty by putting him at the front of the class, speaking loudly and encouraging him to ask for repetition when he doesn't hear something properly.

When a research student with a medical background visited Natnaël at school she noticed that the boy seemed to enjoy his lessons and wrote down what the teacher was saying. What concerned the student was the fact that nobody knew the actual cause of Natnaël's hearing difficulty. She asked herself whether it was temporary or permanent. She discovered that no doctor had ever diagnosed the child and asked his social worker to take him to the local hospital. There, he was referred to a hospital in Addis Ababa since there was no ear, nose and throat (ENT) specialist in Bahirdar. Fortunately, after some research, an ENT doctor was found at a private clinic. He was willing to treat Natnaël at no cost. The hearing difficulties would disappear after a simple treatment of ten days, he said.

Removing barriers

Once the programme staff is aware of the capabilities, needs and rights of persons with disabilities, they can more easily identify disabled people and enrol them in existing projects. However, it is important to realise that inclusion is a process. We distinguish three levels. It starts with presence: for example, children with disabilities are identified and enrolled in schools. The second level is participation: the children with disabilities really participate in the class, are accepted by the other children and the teachers are trained to help them. The last level is achievement: the children with disabilities are able to get a diploma and continue to secondary education.

The first stage of inclusion, presence, is relatively easy to achieve, but the steps towards participation and achievement need more investment and involve more training. Barriers in the programme have to be removed. We should keep in mind here that it is not the person with the disability who needs to adapt him- or herself to the project. We should adjust our projects so all people can access them.

A good example of this is provided by education in Vietnam. There, many schools accept children with disabilities in their classrooms, but often these children are not allowed to sit national exams. The mainstream schools are afraid that they will have a negative influence on their results. In Vietnam it is very important to have high marks as a school and to be the best school in the district or province. So children with disabilities are allowed to participate but their participation is restricted and is therefore not equal.

If we really want to include persons with disabilities in our programmes we should not be satisfied with presence only. Often, it is indeed a milestone that they are present but we need to be sure that they really benefit and participate. We should make sure that they really achieve their goals and dreams. Are children with disabilities equally able to fulfil their dreams, and are adults with disabilities really empowered to use and develop their capacities?

To successfully include persons with disabilities in our projects we need to remove the barriers that prevent them from equal participation. In the first chapter of this guide we explained that there are three categories of barriers: attitudinal, environmental and institutional. Within our projects we can overcome attitudinal barriers by fighting negative attitudes and discrimination. We should remove environmental barriers by creating access for all and we can remove institutional barriers by changing the rules, changing the system.

Inclusion is a process

There are three levels: presence, participation, achievement

Removing barriers is the key to reaching participation and achievement

Beware of separating people with disabilities from other project participants

Don't be satisfied with presence only

Aragash with her friends at school

Aragash's story

Eighteen-year-old Aragash is in the fourth grade. She has been physically disabled since birth. She often feels bullied and neglected by her peers, especially during break time. Nobody wants to chat with her, so she is often alone and that makes her sad. She also feels other children have no attention for her special needs. 'I wish the other children could see that I need to have a chair because I cannot stand for so long,' she explains. 'I need them to be my friends, not to bully me.'

Unlike other parents, Aragash's mother, Demovi, is very strict about her child's education. She realises school must be difficult for Aragash, but will not allow her to drop out. Education is important and she advises other parents to send their children to school. However, the atmosphere in the school classrooms needs to change for the school to become more accessible.

Fighting negative attitudes and discrimination

Often, people with disabilities don't participate in development programmes or community meetings because they face discrimination from other members of the community. They are called names and not taken seriously. In schools, this results in bullying or being ignored by fellow students. The only way to overcome this discrimination is by raising awareness in the community and in the project. There are different ways to do this, depending on the nature of the project.

Bullying in schools is a big problem for children with disabilities. If you want to include children with disabilities in your school programmes, sensitisation of school children and their parents should take place.

It is not only the community that can discriminate against persons with disabilities. It is also important that all the staff working in the programmes have a positive and welcoming attitude towards them. So all the teachers, field workers, school heads, technicians, doctors – even the drivers – should be trained on the issue.

↑
Everyone needs to be trained in dealing with people with disabilities

Creating access for all

Physical access

If persons with disabilities can't access the building, meeting place or water tap, they simply can't participate in your project. So if you want to make your project inclusive, you have to address the issue of physical access. This may sound like a costly exercise, but it doesn't have to be. Very often there are inexpensive solutions available. A classroom can be made accessible by making a small ramp of cement or mud, or simply move the class in which a physically disabled child is participating to the ground floor. Make sure that community meetings take place at a location that can be accessed by people who use a wheelchair. Special attention needs to be paid to the accessibility and hygiene of toilets. This is especially important for women and girls with a disability.

If access for persons with disabilities is taken into account during the design of new infrastructure, there are hardly any extra costs.

There are standards available for designing accessible buildings, houses and other structures. This is called Universal Design. The CBM guideline on accessibility is a very useful tool to make built structures accessible. http://www.cbm.org/article/downloads/54741/CBM_Accessibility_Manual.pdf

← Resources are available

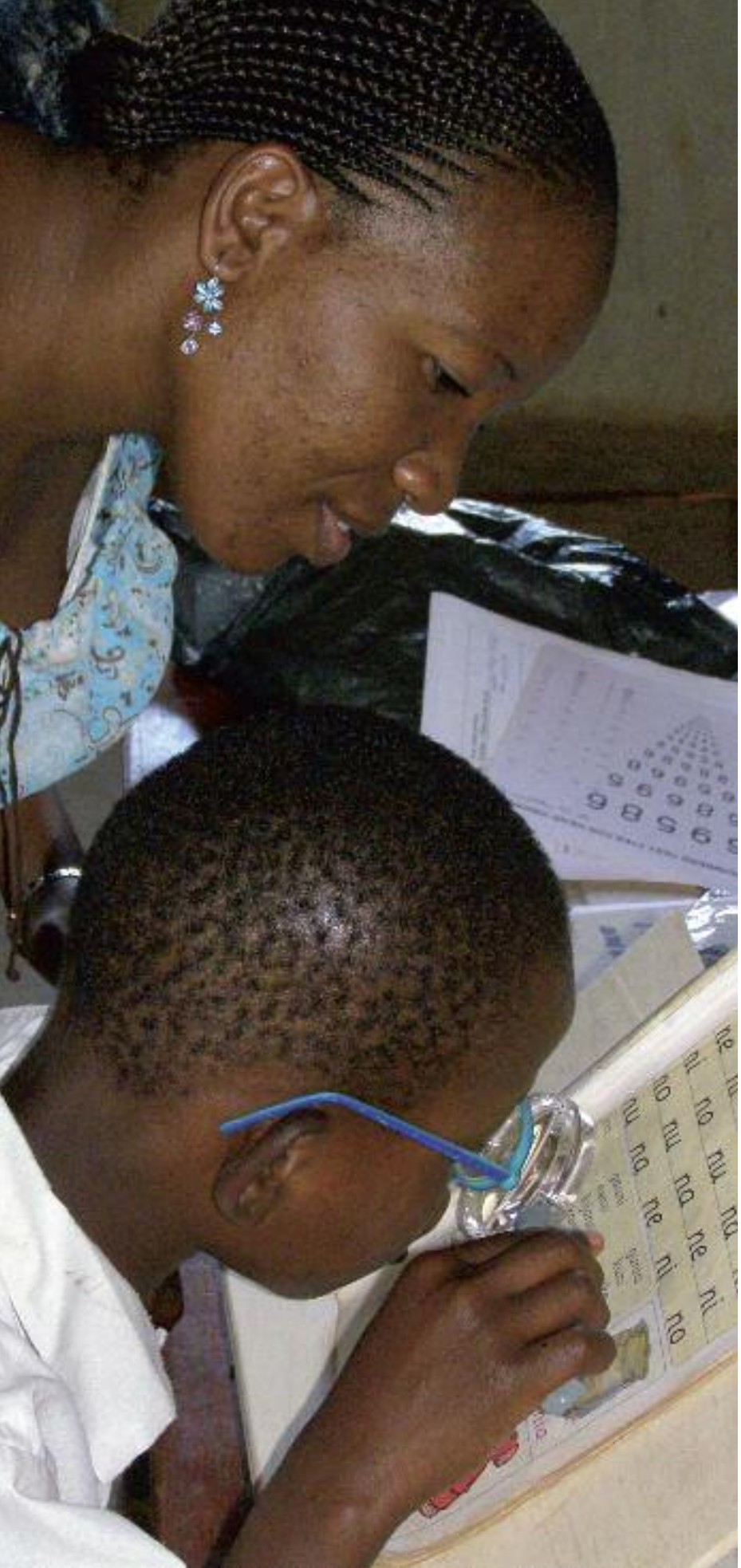
However, ensuring accessibility is an on-going process. People with disabilities, their family members and the community can and should play an important role in making projects accessible.

Accessibility problems can also be overcome by making sure that persons with disabilities receive assistance. This can be from a family member or neighbour who is taking the disabled person to the meeting. Or student peers who accompany their disabled classmate on their route to school. Make sure that the person with the disability feels comfortable with the arrangements.

Access to information

Accessibility of information is very important for people with visual or hearing impairments. If written information is provided, make it available in communication formats (Braille, large print or audio) suited to blind people. Audio is usually a better format as many people with a visual impairment never learnt to read and write Braille. It is also helpful to let people who are blind touch objects so they can gather tactile information. If you want to explain to a person who is blind how to use a condom, it will be easier for them to understand if they can touch

← Disabled people often lack information



the condom and practice on an artificial model. Otherwise it will be difficult for them to understand.

Use a sign language interpreter if there are people with hearing impairments. This may be a challenge: there may not be many sign language interpreters available in your country. You could find out from the person with the hearing impairment if his or her family could assist with the interpretation. In school settings it is helpful if teachers get a basic introduction to sign language and Braille. Usually special schools or government resource centres are able to organise such training and advise on adjusted school materials for children with disabilities.

If persons with intellectual disabilities participate in your programme, avoid using long sentences and difficult words. This will help them to better follow what is being said and to better understand it as well. If necessary, you can ask a family member to accompany them during meetings. Repetition and practice is important for them to learn new things.

↑ *Teachers should get basic training in Braille and sign language*

↑ *Don't use long sentences and difficult words*

Change discriminatory rules

If there are discriminatory rules in projects, these need to be removed. One of the participating organisations in Ethiopia got stuck while including children with disabilities in their Child Sponsor programme, because one of the admission criteria set by their donors was that children should be able to learn and should be able to go to school alone. In the discussion that followed, programme staff came to the conclusion that they should take a stand in relation to their donor and break the rules.

There can, however, also be discriminatory education or employment laws in your country or district: for example, not allowing extra time for children with disabilities during examinations or excluding persons with disabilities from the vocational training curriculum. If you come across discriminating laws or practices, please consult disabled peoples' organisations in your country or district and see what you can do together to help the government to change the system.

Inclusive education needs more attention

Education is important for every individual, but even more so for children and adults with disabilities. They may not be able to perform heavy manual labour because of their disability and so need to work with their minds in order to make a living. Our experience is that including persons with disabilities in food-security programmes, emergency relief or water and sanitation projects can quite easily be achieved. However, including children with disabilities in regular schools requires more time and investment. We would therefore like to pay additional attention to inclusive education in this guide.

Identifying children with disabilities and including them in regular classes is relatively easy. But more is needed to ensure that they really participate and make achievements. The school environment has to be made accessible, including the toilets. Raising awareness amongst other children and their parents is essential to prevent bullying and create a safe environment for them.

← *Create a safe environment without bullying*

But that is just the beginning. The teachers need training on how to teach children with disabilities. They need to learn how to teach a blind child, a deaf child and how to deal with children with other disabilities. This kind of training can be received from the Ministry of Education – or there may be training available at special schools. Apart from this, it is also important that teaching materials are available for children with disabilities: Braille materials, spoken books and so on. Networking with the government, disability-specific NGOs or disabled-people's organisations is essential here. In some countries there are inclusive education networks that can help your organisation get access to training and resources.

←← *Laws can have a discriminatory effect*

← *Inclusive education networks can help you access resources and training*

Teachers must be trained to deal with children with disabilities

If inclusive education seems to be impossible because of a serious lack of special needs educators, you could start thinking about setting up alternative systems. These may not be ideal but may be appropriate for the time being. Some countries use itinerant or peripatetic teachers who come once in a while to visit the schools

←← *Education is even more important to children with disabilities than to others*

→→ *Specialists who visit and advise teachers*

that fall under their jurisdiction. These peripatetic specialists advise teachers and screen and assess children for developmental delays, learning disabilities or other invisible disabilities such as partial deafness or impaired vision. Sometimes with simple advice that costs nothing (for example, placing the child in the front row of the class, close to the teacher) they can make a great difference in the life of the child and the teacher.

There may be situations where a child with a disability will benefit from special needs education and should be referred to a special school. This should be a last resort, however, and should only be done when it has become evident that the child is not coping in the inclusive classroom. While we do not promote special needs education, we do realise that some children may benefit more, especially when the quality of inclusive education available is so poor that the child with special needs won't learn.

→→ *Connect with adult literacy programmes*

Many adults with disabilities are illiterate because they were not able, or did not get the opportunity, to go to school. While this is something that cannot easily be redressed, it is strongly recommended that illiterate adults with disabilities be offered the opportunity to follow literacy classes. It is important to connect with literacy programmes and lobby their management to include people with disabilities. The rewards will be tangible as you will be empowering adults, helping them to get better opportunities to contribute to their families and society. You can help equip them to take on leadership roles in community-based organisations and development when you develop better conditions for them to become employed.

Building networks

'If spider webs unite they can tie up a lion' (Ethiopian proverb)

Realising the full participation of people with disabilities in society is the responsibility of all: the government, the community, disabled people and their organisations, development and humanitarian agencies as well as disability-specific organisations and services providers. No one single organisation will be able to achieve the development of a (more) inclusive society. All hands need to be on deck to achieve this dream.

The development of programmes that include persons with disabilities requires that organisations build stable partnerships with others. Mainstream organisations don't need to become disability-specific service providers. They only need to open up their programmes to persons with disabilities, make services accessible and refer for disability-specific interventions when needed.

Since many mainstream development organisations are new to the topic of disability they often lack a network of disability-specific service providers and disabled people's organisations in their working area. This chapter will help you identify potential stakeholders that can support your organisation in making its development programmes inclusive.

The following table shows the different stakeholders in the inclusive development process, their role in inclusive development and the topics on which you can link up with them. It is not an exhaustive list, and the situation will differ per country, but it gives you an idea of the different players in the field.

Disabled people's organisations are indispensable partners

Disabled people's organisations (DPOs), mainly set up in the past 30 years, are a major tool for countering exclusion and discrimination. They sometimes represent a search for emancipation among people with disabilities. In some countries, DPOs have become powerful and politically driven organisations.

DPOs usually see themselves as human rights movements. While this is probably true for most national DPOs, more local, community-based DPOs are in fact less politicised and more practically oriented. Often, they keep themselves busy striving for economic empowerment via self-help groups rather than

↢↢ *Organisations have to build stable partnerships*

↢ *DPOs can become powerful human rights advocates*

↢↢ *Identify potential stakeholders that can give you support*

Role of different stakeholders in inclusive development

Stakeholders	Role in inclusive development	Link up for
Disabled people's organisations	Lobby and advocate for the rights of persons with disabilities	• Identification of persons with disabilities • Disability data • Training of staff • Awareness-raising in communities • Lobbying local government • Referral of persons with disabilities to self-help groups (for empowerment)
Government	Ensure access to basic services for persons with disabilities – bring laws and legislation in line with UNCRPD	• Disability data • Medical and rehabilitation services for persons with disabilities • Access to government programmes and safety nets • School curriculum development • Teacher training
Disability-specific services providers, such as community-based rehabilitation programmes, special schools, disability-specific NGOs	Provide medical and rehabilitation services Organise disability-specific programmes Empowerment of persons with disabilities and their organisations	• Provision of medical care and rehabilitation services • Counselling and assessment • Provisions of devices such as wheelchairs and crutches • Information in accessible format (Braille or sign language) • Technical expertise • Disability data • Identification of persons with disabilities • Staff training • Teacher training • Lobby and advocacy
Mainstream development organisations	Open up programmes to persons with disabilities Refer for disability-specific needs	Referral of persons with disabilities to be included in their development projects.

getting involved in local or national politics. But the more they develop, the more such DPOs become engaged in awareness-raising and advocacy and become a mouthpiece for those whose rights are being violated. In some countries, such as Bangladesh and India, local DPOs may form federations or coalitions, which have a stronger voice. They foster active citizenship and together with, or under, a national umbrella organisation, they may be very successful in combating social injustice. The joint effort of DPOs in South India, for instance, helped to successfully fight corruption at pension payout points. The years of corruption – where people with disabilities had to pay a certain percentage of their disability pension to the postmaster in charge of issuing the pension – stopped after intensive advocacy from the joint DPOs in that region.

When cooperating with DPOs it is good to be aware of the following. Some national DPOs, though politically powerful, may have alienated themselves from their constituency as they are usually based in the capital cities and managed by the urban elite. Many local DPOs may be organisationally weak and have to struggle for their own survival. Additionally, many DPOs represent people with one type of disability only.

Should all the challenges described above prevent us from forming partnerships and working closely together with DPOs? The answer is a clear and unequivocal no. We won't be able to move towards a better society for all if we ignore DPOs. The contributions of national DPOs in many countries have formed a powerful force to convince governments to sign and ratify the UNCRPD. Local DPOs are often beacons of hope for people with disabilities, providing meeting places where they come into contact with others who face similar challenges. They are part of a larger palette of civil society organisations that are vital in building society and learning democracy.

DPOs can help you to identify, and thus include, persons with disabilities in your activities. They also can play a role in staff training, raising community awareness or lobbying the local government. If your organisation focuses on strengthening civil society, it would be great if, in return, you can support DPOs to strengthen their organisations and help them to effectively play their role as civil society bodies.

Cooperation with government

Why we should cooperate with our governments doesn't need much explanation. If your government has ratified the Convention on the Rights of Persons with Disabilities they have to

«« But they can sometimes become alienated from their constituency

«« DPOs provide meeting places for people with disabilities

→ *Help disabled people to access government services*

bring laws and legislation in line with the convention. In many countries, there is a separate disability act that promotes the rights of persons with disabilities. It is also the role of your government to ensure access to basic services, such as education, healthcare and rehabilitation services.

It is, however, your task to help the persons with disabilities in your project to access the schemes and services offered by the government. Help them to get a disability card so they can use the related benefits. Refer persons with disabilities to government clinics and rehabilitation schemes. Some governments have even set up resource centres for inclusive education that support the inclusion of children with disabilities in regular schools.

→→ *Other NGOs can help*

[subheading 2] Disability service providers

Disability service providers such as hospitals, orthopaedic workshops, rehabilitation centres and community-based rehabilitation programmes, but also special schools, are very important resources and should be used for referral purposes. They can offer assessments, counselling services, advice, consultation and the necessary therapeutic and rehabilitation services that may be needed. They can also play a role in staff training, teacher training or the provision of accessible information like Braille and sign-language interpretation.

→ *Continuous investment in partnerships is necessary*

An emerging trend in many countries is the introduction and development of so-called Community Based Rehabilitation (CBR). This is a strategy that aims to improve the quality of life of persons with disabilities. It involves working closely with persons with disabilities, their families and service providers to remove barriers that result in exclusion from participation in community life. CBR programmes are often run by NGOs or governments. It is of importance to connect with existing CBR programmes and become part of their multi-sectoral network. You can refer people with disabilities to the CBR programme for their disability- specific needs while the CBR programme, in turn, can refer persons with disabilities to be included in your development programmes. This will certainly lead to a fruitful cooperation.

Community Based Rehabilitation programmes and schools can also work together on inclusion. The CBR programme focuses on changing negative attitudes towards children with disabilities. It can give awareness workshops for schoolchildren about disability in the classroom. The school can welcome the children, make its facilities accessible and find practical solutions for adaptations – together with the CBR programme.

Referral to other mainstream organisations

Last but not least, you could also refer persons with disabilities and their family members to the programmes of other development NGOs. If you include a disabled child in your school but the family is living in very poor conditions, try to get them enrolled in an income-generating project. Or refer disabled persons who cannot read or write to a literacy programme.

We would like to conclude by saying that true partnership will lead to mutual learning, exchange of knowledge and expertise, and will greatly contribute to successful inclusive development. However, partnerships require continuous investment from all partners. One-sided love will not work!

Help them get enrolled in income generating projects

[31]

Becoming a disability-inclusive organisation

What does an inclusive organisation look like?

→ *Organisational change is essential for sustainability*

Most development organisations start the process of disability mainstreaming with a pilot project. That's exactly what we did in our learning programme. We started by including persons with disabilities in pilot projects in order to learn more about the whole process of inclusion. We soon discovered, however, that pilot projects alone do not engender sustained attention to the inclusion of persons with disabilities in our programmes. That requires organisational change. Including people with disabilities doesn't only involve inclusion in projects and programmes, but also our organisational values, systems and policies. Barriers to equal participation exist not only within our projects but also in our own policies, offices and websites.

We also came to the understanding that it was essential to anchor the inclusion of persons with disabilities in the policies, structures and systems of our own organisations or the issue would eventually disappear from the agenda.

For sustainable change we need not just disability-inclusive projects, but also disability-inclusive organisations. But what are the criteria of a disability-inclusive organisation? And what kind of change process is needed to become a disability-inclusive organisation?

→→ *Dare to do the test!*

During the Thematic Learning Programme we developed a short checklist that helps determine how disability-inclusive an organisation is. It was designed for European development organisations that work with local partner organisations and often function as donor organisations. Some questions may not be completely applicable to your own organisation, but the checklist will give you an impression of where your organisation stands.

Do not be shocked if your organisation only scores Level 1 or Level 2 in the test. The organisations that joined the Thematic Learning Programme also started with low scores. But within two or three years some organisations are already getting to Levels 3 and 4. So quick progress can be made in making your organisation disability inclusive.

How inclusive is your organisation?

Area	Level 1	Level 2	Level 3	Level 4
Policy	Disability or inclusion of persons with a disability is not included in our strategy documents, or in our sectoral policies.	Inclusion of marginalised groups is mentioned in the strategy documents and sectoral policies, but not specifically worked out.	Inclusion of persons with disabilities from a rights-based perspective is mentioned in the strategy documents and worked out in some sectoral policies.	Inclusion of persons with a disability from a rights-based perspective is a crosscutting issue in our organisation and worked out in all our strategy documents and sectoral policies.
Human-resource management	No human-resource diversity policy available in the organisation. No actions taken to employ persons with a disability.	Diversity policy available in the organisation, but disability is not mentioned there.	Disability is mentioned in human-resource diversity policy.	Disability is mentioned in human-resource diversity policy and affirmative actions (for example, placing job announcements in disability networks) are taken to employ persons with a disability.
	No staff, board members or volunteers with a disability in the organisation.	At least 1% of staff, board and volunteers consist of persons with disabilities.		At least 2% of staff, board and volunteers consist of persons with disabilities.
Planning, Monitoring and Evaluation	Disability data is not collected in any programme.	In less than half of the programmes disability data is collected.	In more than half of the programmes disability data is collected.	Disability data is collected in all programmes.
	Disability is not mentioned in planning, monitoring and evaluation formats.[1]	Disability is mentioned in some planning, monitoring and evaluation formats.	Disability is mentioned in majority of planning, monitoring and evaluation formats.	Disability is included in all relevant planning, monitoring and evaluation formats, including the annual report of the organisation.
	Persons with disabilities[2] are not involved in the design, planning, monitoring and evaluation of programmes.	In less than half of the programmes persons with disabilities are consulted in the design, planning, monitoring and evaluation.	In more than half of the programmes persons with disabilities are consulted in the design, planning, monitoring and evaluation.	Persons with disabilities are involved in the design, planning, monitoring and evaluation of all programmes.
Programmes	The number of beneficiaries with a disability in regular programmes[3] is negligible.	1-3% of the beneficiaries in our regular programmes are persons with a disability.	4-5% of the beneficiaries in our regular programmes are persons with a disability.	6% or more of the beneficiaries in the regular programmes are persons with disabilities.[4]
	There is no collaboration with disabled people's organisations and disability service providers (including government) in our programmes	In less than half of the programmes collaboration takes place with disabled people's organisations and disability service providers (including government).	In more than half of the programmes collaboration takes place with disabled people's organisations and disability service providers (including government)	All programmes collaborate actively with disabled people's organisations and disability service providers (including government)
	No budget is allocated for inclusion of people with disabilities in our programmes.	0-1% of budget is allocated for inclusion of persons with disabilities in our programmes.	2% of budget is allocated for inclusion of persons with disabilities in our programmes.	3-7% of budget is allocated/available for inclusion of people with disabilities in our programmes or projects.

Area	Level 1	Level 2	Level 3	Level 4
Lobbying/ advocacy/ networking	The rights of persons with disabilities are not included in the organisation's existing lobbying, advocacy or networking activities.	The rights of persons with disabilities are included in some of the organisation's existing lobbying, advocacy or networking activities.	The rights of persons with disabilities are included in the majority of the existing lobbying, advocacy or networking activities.	The rights of persons with disabilities are included in all existing lobbying, advocacy or networking activities of the organisation.
Accessibility	The organisation's office building and meeting rooms are not accessible to persons with disabilities.	The meeting rooms and toilets are accessible to persons with disabilities. The workspaces are not accessible.	The meeting rooms, toilets and part of the workspaces are accessible for persons with disabilities.	The whole office, including all workspaces, meeting rooms and toilets, are accessible to persons with a disability.
	Accessibility is not taken into account when events[5] are organised by the organisation. Only a small proportion of the events are accessible to persons with disabilities.	Accessibility is not taken into account when events[6] are organised by the organisation, but 50% of the events are accessible to persons with disabilities.	Accessibility is taken into account when events are organised. The majority are accessible to people with disabilities.	All events organised by our organisation are accessible to people with disabilities.
	The website and other information sources are not accessible to persons with visual impairments.	The website is tested for accessibility and is partly accessible. Newsletters and information are made accessible on demand.	The website is tested for accessibility and is fairly accessible. The option of getting newsletters and information in an accessible format is actively communicated.	Website is fully accessible and newsletters/brochures are available in accessible formats.
	No accommodation is made for people in need of sign language interpretation.	Sign language interpretation is available on demand.		Sign language interpretation is always provided as an option.
Capacity building	No orientation is so far given to staff of the organisation on the rights of persons with disabilities and inclusion in regular programmes.	Some staff received a one-off orientation on the rights of persons with disabilities and inclusion in regular programmes.	Majority of staff received a one-off orientation on the rights of persons with disabilities and inclusion in regular programmes.	Staff regularly receives orientation on the rights of persons with disabilities and on inclusion in regular programmes. Staff members are encouraged to actively work on inclusion of persons with disabilities.
	Inclusion of persons with disabilities is not discussed with local partner organisations.	Inclusion of persons with disabilities is discussed with local partner organisations.	The organisation is offering orientation on the rights of persons with disabilities and on inclusion of persons with disabilities to local partner organisations	The organisation is systematically offering orientation on the rights of persons with disabilities and on inclusion of persons with disabilities to their local partner organisations.

1. Think of baseline studies, proposal formats, reporting formats, field-visit formats, evaluation formats, annual report and so on.
2. Or in case of children, their caretakers might be involved in the design of programmes.
3. 'Regular' refers to non-disability-specific programmes.
4. People with disabilities in programmes: this includes caretakers of people with disabilities if the person with the disability is not able to participate.
5. Events can be seminars, conferences and training courses, but also sponsored activities such as concerts or sponsored walks.
6. Events can be seminars, conferences and training courses, but also sponsored activities such as concerts or sponsored walks.

How to become an inclusive organisation

You may have done the above test and come to the conclusion that many things need to be done to make your organisation disability inclusive. Here we offer information on how to organise a successful change process. There are many theories about how organisations change and how you can plan and manage a change process. We will use Kotter's eight-step change model.[4]

Eight steps to organisational change

Step 1 – Create urgency
Step 2 – Form a powerful coalition
Step 3 – Create a vision for change
Step 4 – Communicate the vision
Step 5 – Remove obstacles
Step 6 – Create short-term wins
Step 7 – Build on the change
Step 8 – Anchor the changes in the organisation

Kotter stresses that change in an organisation does not occur overnight, but requires hard work. Careful planning and the building of a solid foundation are vital to making implementation easier and will improve the chance of success. Pitfalls for change agents are impatience and too high expectations.

A change process can be planned

Create urgency

A sense of urgency about the need for change has to develop in the entire organisation. According to Kotter, at least 75% of an organisation's management needs to 'buy into' the change for it to be successful. This means that Step 1 is crucial. Significant time and energy need to be invested to build this sense of urgency before moving on to the next steps. It is often not just one thing that leads to this feeling of urgency but a combination of factors.

For EFICOR in India, the earthquake in Gujarat was a starting point. Executive director Rev. Kennedy Dhanabalan explains:

'During the relief operation after the earthquake in Gujarat in 2001, EFICOR realised that they needed to ensure that disabled people were given special focus in relief operations. It was noticed that people used to fight and run behind trucks to receive food materials. The disabled were not able to do so and they were left behind. After that

75% of management needs to buy into the need for change

experience, we started to pay attention to persons with disabilities in our Disaster Risk Reduction programmes. For example, training staff to rescue persons with disabilities and making shelters accessible.

'Also, in one of our campaigns we chose to focus on vulnerable groups, including persons with disabilities. So it was a very logical step for us to join the capacity-building programme offered by our donor, Tear Netherlands. In our organisation we want to practice what we preach, so we seriously want to work on mainstreaming disability.'

→ *Sense of urgency needs to be built up*

The executive director discussed the idea of disability mainstreaming with his board and they gave the green light to draft a policy on disability mainstreaming.

The emergency relief was a starting point, but the sense of urgency also resulted from the focus EFICOR placed on vulnerable groups, the culture of the organisation to practice what it preaches and an invitation from a donor to join a capacity-building programme.

→→ *A project team consisting of people from different departments seems to work much better than a focal person operating alone*

For the Emanuel Hospital Association in India, the urgency to do something for people with disabilities started when one of the managers had a child with a disability. He suddenly became aware of the needs of children with disabilities and wanted to do something. The organisation started providing institution-based rehabilitation services to children with disabilities. After a couple of years, organisers realised that they would be more effective if they worked in communities and paid attention to disability in all their programmes. From there, EHA started mainstreaming disability in all projects.

→ *Link inclusion of persons with disabilities to the core strategy of your organisation*

But this sense of urgency does not occur automatically in all organisations. Sometimes it can be quite an intensive process to convince the management of an organisation that there is an urgent need to include persons with disabilities. It often helps to link inclusion of persons with disabilities to the core strategy of your organisation. So if your organisation is aiming to reach marginalised groups, show that persons with disabilities are a marginalised group. If your organisation is working on human rights, focus on the rights of persons with disabilities. If the motto of your organisation is 'education for all', explain that one-third of the children not going to school are children with disabilities. In the chapter 'How to get commitment within your organisation' we will discuss in more detail how this sense of urgency can be created in development organisations.

Form a powerful coalition

To convince people that change is necessary, strong leadership and visible support from key people within the organisation is needed. A coalition or team of influential people needs to be brought together whose power comes from a variety of sources, including job title, status, expertise and political importance. The 'change coalition' needs to work as a team and continue to build urgency as well as momentum around the need for change.

In our Thematic Learning Programme, we train focal persons to stimulate and oversee the process within their organisations. We have learned that the selection of the focal person is crucial. He or she should really be appointed and have time allotted to guide the disability-mainstreaming process within the organisation. He or she should also be in the right position to keep the process going. And last but not least, the focal person needs to have the commitment and the support of higher management. Some organisations work with a project team

consisting of people from different departments. That seems to work much better than a focal person operating alone. This is especially true for large organisations.

EFICOR India works with a team. The organisation appointed two focal persons responsible for keeping the topic on the agenda, developing strategies and overseeing implementation. The executive director supports the focal persons as much as he can, for example by joining training sessions or holding debriefings with the focal persons after training sessions.

'I chair a sub-group on inclusive education,' says the executive director of NVEA, Ethiopia. 'In this group, we share experiences and discuss how to expose colleagues to the idea of including children with disabilities in education. We play a major role in raising awareness among the others.'

The good news, however, is that a motivated 'self-assigned' focal person can still do a lot of lobbying in his or her own organisation and succeed in getting inclusion on the agenda. So if you are a lone voice but enthusiastic to make a change in your organisation, try to convince key people first and make them your allies. Create a team to promote inclusion at different levels.

Create a vision for change

A clear vision of the change you want can help people understand why they need to do something differently. The information and instructions they are given tend to make more sense then.

It is important to make a simple plan about how your organisation is going to work on inclusion of persons with disabilities. This starts with setting a clear goal: for example, by stating that persons with disabilities are considered part of your target group and you strive for equal participation in all your programmes. If possible, develop this plan together with your colleagues. They will feel they are owners of the change process if they have participated in the design of it. We learned in the Thematic Learning Programme that it is important to reduce the process of inclusion to simple and concrete steps, so present a clear strategy and explain what is expected from everyone.

EHA in India, for instance, has developed a very catchy vision for change. They use the slogan 'Learning to see, Learning to do, learning to let live, Learning to love'. All activities related to disability inclusion fall under one of these categories. 'Learning to see' stands, for example, for training and sensitisation of management and project staff and for identification of persons with disabilities via assessments and surveys. 'Learning to do' refers to inclusion of disability in all training materials, manuals and monitoring reports. As a result of that, disability is automatically included in all project activities. 'Learning to do' also encourages project staff to help persons with disabilities to get access to government entitlements, such as working 100 days per year or pensions.

Communicate the vision

The vision needs to be communicated frequently and powerfully, and be embedded within everything you do. If the vision is referred to daily when decisions are made and problems solved, people will remember it and respond to it. It is important to 'walk the talk': what you do is far more convincing than what you say.

Dave Lipton at www.crippencartoons.co.uk

↢↢
Make key people your allies

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What you do is far more convincing than what you say

↢↢
Set a clear goal

→→ *Don't rush to declare victory: real change takes time*

Communicating the vision of inclusion can be done in many different ways. Of course the more formal way is by organising a training session for staff, but you can also highlight the topic of inclusion in more informal ways, such as during staff meetings, devotions or during a team outing. You can find more information about this in the Raising awareness chapter of this booklet.

Remove obstacles

Some people are resistant to change and some processes and structures will block the way. It is important, therefore, that obstacles are removed so that people are empowered to implement the vision. There are quite some excuses around to prevent us from taking action. 'Inclusion of persons with disabilities is too costly'; 'The donors don't like it'; 'We already have so many other issues to deal with'. In the section on how to get commitment in your organisation we will explain how this resistance can be overcome.

Create short-term victories

→ *Pilot projects can inspire wider change*

Success is a prime motivating factor. Some visible victories early in the change process will inspire people. Without these, staff may lose interest or even attach negative associations to the change process. [9]

In the Thematic Learning Programme we used pilot projects in Ethiopia and India as short-term victories. This worked well: within a relatively short time organisations were able to include people with disabilities in their projects. Many development organisations prefer to start with pilot projects and then use their experience to anchor the focus on disability in their organisational structures. A pilot project can also be used to convince senior management of the viability of including persons with disabilities. Seeing is believing!

→→ *The changes have to become part of routine practice*

Build on the change

Because real change takes time, Kotter advises against declaring victory too soon. Quick successes are only the start of the process towards long-term change. Keep looking for improvements, as each success provides an opportunity to build on what went right, as well as what needs to be improved. Inclusion cannot be reached overnight; we constantly need to overcome barriers. So don't stop after you have successfully completed one pilot project: use it to learn how to make other projects and the entire organisation more disability friendly. It is our experience that it can take five years before organisations have really embedded disability in their entire structure. Just take it step by step.

Anchor the changes in the organisation

The changes should become embedded in, and part of the routine practice of, all aspects of the organisation. The values behind the vision must be visible in day-to-day work. Bring policies and systems in line with the new vision so people are automatically empowered to implement it.

This is a very important aspect. If inclusion of persons with disabilities is anchored in organisational systems such as in planning, monitoring and evaluation or in all training manuals, the topic will come back automatically in the day-to-day work. In the Anchoring disability in the organisation chapter we will explain how you can include disability in the overall policies and strategies of your organisation; how to include disability in the existing monitoring system; and how to make the human-resource management of your organisation disability friendly.

EFICOR in India, for instance, recently drafted a policy on disability mainstreaming. Executive director Rev. Kennedy Dhanabalan explains:

‘We want to include persons with disabilities in all our programmes and hire persons with disabilities as staff. We will create special positions to ensure that they do not drop out due to heavy competition. Disability will also be included in all training programmes of EFICOR. So the topic will not only be included in training of our own staff, but also in the training of other organisations. The process of making EFICOR’s office accessible is already underway. We are now waiting for the owner to give approval to build a ramp and accessible toilets.’

How to get commitment in your organisation

An important lesson from the Thematic Learning Programme is that it takes time before organisations are willing and able to fully commit to the inclusion of persons with disabilities. We had lengthy discussions on how we could get full commitment from our colleagues and management to mainstream disability throughout the whole organisation. We came across many stubborn excuses and obstacles for not including persons with disabilities. If you want to get commitment in your organisation you first have to tackle these excuses.

Handling common excuses for ignoring people with disabilities

↓ The excuses for not including people with disabilities can be deeply entrenched

Excuse 1 – it's not cost effective

People don't believe including people with disabilities is cost effective. They ask: 'Why should we invest a lot of money in persons with disabilities? We can only spend our money once. Our targets will slide if we include persons with disabilities.'

→ This excuse is based on false assumptions

Some false assumptions lie under this reasoning. First of all, there is the idea that inclusion of persons with disabilities is very costly. People often envision high expenditure for assistive devices, surgery, financial support or customised transportation. This idea is rooted in the medical approach to disability, which defines disability as a medical problem that can only be fixed with expensive treatment, devices and special training programmes. Of course, there are costs related to the inclusion of persons with disabilities in regular programmes, but these costs are not that high. 2-7% of the programme budget has been

sufficient in the examples we have come across. These are the costs of making the programmes accessible to persons with disabilities. For disability-specific interventions, mainstream organisations should refer to other service providers.

'When we did a needs assessment on the inclusion of children with disabilities in our schools we found that there was a need for crutches and other assisting devices,' says the executive director of RLDO, Ethiopia. 'We were worried that we could not afford to buy these things. However, at our annual board meeting, I suddenly realised that the director of Handicap International in our region was part of our board. Fortunately they were just planning to extend their services to our area. We are now discussing how we can help each other.'

Another underlying assumption in the cost effectiveness debate is that persons with disabilities cannot perform as efficiently as other people do. This idea is rooted in the charity approach towards disability in which persons with disabilities are defined as weak, dependent and unable to perform. This is not correct. Most people with disabilities can perform like any other person as long as the barriers that hinder their participation are removed. When people are talking about costs they often forget that persons with disabilities have the right to be included. We don't talk about costs if we include women in development. We don't talk about costs if we include children. So why would we talk about costs if persons with disabilities need to be included? If persons with disabilities are seen as part of the target group, the whole debate about extra costs will probably disappear or can be brought down to the basic costs of making projects accessible.

In development cooperation, it is much cheaper and more sustainable to mainstream disability in development programmes than to create ad hoc, project-based, disability-specific interventions. Mainstreaming is cheaper because it relies on existing infrastructure. Schools are already present, for example. The only issue is to make them accessible. Another benefit is that inclusive development reaches more persons with disabilities in their own communities. This creates social acceptance within the community. Building special institutions, hiring medical professionals and importing technical equipment costs a lot of money and only reaches a small percentage of the people who need it.

If the cost-effectiveness argument is strong in your organisation it will probably help to organise an awareness session in which you emphasise the different approaches to disability and discuss what inclusive development implies.

← *It is much cheaper to mainstream disability than create disability-specific interventions*

The costs of exclusion

- Long-term loss of productive potential of disabled person due to lack of appropriate rehabilitation, education and vocational training opportunities.
- Additional costs to the family, community and State in caring for the disabled person who could have become independent.
- At family level: loss of income because time is needed to take care of disabled family members. Children of parents with a disability miss school because they have to care for their parents or there is no money to go to school.
- Additional medical costs that could have been avoided by basic exercises or rehabilitation that prevents impairments becoming worse – for example, corrective surgery for contractures due to cerebral palsy or post-polio

Excuse 2 – we don't have the expertise to do it

The underlying idea behind this excuse is that people with disabilities can only learn and make progress if they are guided by experts with a lot of disability knowledge. Our experience is that 80% of persons with disabilities can participate in social life without any specific additional intervention, or with low-cost and simple community-based interventions that do not require any specific rehabilitation expertise.[5]

The other 20%, who cannot actively participate in and benefit from mainstream development programmes without specific measures (for example, providing prosthesis or wheelchair, physiotherapy or surgery), can and should be referred to disability-specific organisations,

→→ *An open discussion can clarify thinking about disability*

such as orthopaedic workshops, physiotherapy services and special needs education. These specific service providers can deliver the necessary interventions and equipment or make the necessary adaptations.

Excuse 3 – we are already overloaded; we don't have time for another issue

This obstacle we found most difficult to tackle. How to deal with this very understandable viewpoint? Of course development practitioners are busy with many different issues, such as climate, gender or rights. So we understand that people are not happy with an addition. The best way to deal with this obstacle in your organisation is to link the inclusion of persons with disabilities to its core mission. This can be education for all or reaching out to the poorest of the poor. The time you spend on fulfilling your core mission is not usually considered extra workload.

Another way to deal with time shortage is to start including disability in the activities you already do. So if you are organising a partner conference, include a workshop on inclusive development. If you have to collect real-life stories for the next newsletter of your organisation, include a life story of a beneficiary with a disability. If you are reviewing the education policy of your organisation, write a chapter about inclusive education. If you have to approve a new proposal from a partner organisation, ask them what they will do to include persons with a disability.

Excuse 4 – we need to sort out the problems of 'normal' people first

This is a common excuse. People complain that fighting poverty is difficult enough. Why should we make it more complicated for ourselves? We can counter this excuse by explaining that people with disabilities are normal people with

normal needs. Development organisations should focus on people who are excluded and oppressed. So this kind of reasoning probably isn't in line with the core mission and values of our organisations.

Excuse 5 – our donor is not interested in the inclusion of persons with disabilities

Implementing organisations in the South are often reluctant to include disability in their proposals, because they are afraid that their donor will not be interested or will reject the proposal because of increased cost. They are unsure about starting the discussion on inclusion of persons with disabilities with their donors. From donor organisations we sometimes hear: 'We will only start working on inclusion of persons with disabilities if our partner organisations ask for it.' So who should take the first step? WCAT in Ethiopia took this step and found it quite easy in the end.

In its child labour programme funded by Kinderpostzegels, WCAT includes children with disabilities because they work as well. The donor is enthusiastic about this focus, since WCAT explained the importance of this issue in the context of Ethiopia, where many children with disabilities are forced to work. According to WCAT, Kinderpostzegels sees the importance of including these children in fighting child labour in Ethiopia.
Institutional donors like The World Bank, USAID, the European Union and DFID have recently showed their interest through funding opportunities specifically aimed at the inclusion and rights of marginalised groups, including persons with disabilities. With the ratification of the UNCRPD, large donors such as the European Union are obliged to ensure the equal participation of persons with disabilities. This is visible in their guidelines for applications.

However, not all donors are aware of the need for inclusion of persons with disabilities. The Dutch Ministry of Foreign Affairs has been very hesitant concerning this subject. And the current economic climate does not ease this process.
We think that mainstream development organisations have a role to play in this discussion. Only when the need for funding of inclusion is expressed will donors start approving applications. 'We need to challenge donors when they do not want to accept a budget line for inclusion of persons with disabilities,' says Sue Coe, coordinator of disability mainstreaming at World Vision. 'As long as NGOs do not show the costs, nobody will know.'

Perhaps you have come across other reasons why inclusion of persons with disabilities isn't happening. Here we focused on excuses and obstacles at the organisational level. Personal assumptions about the source of disabilities and the capabilities of persons with disabilities may also be blocking inclusion. Our experience has taught us that an open discussion can clarify thinking about disability.

← *Large donors like the European Union are obliged to ensure the equal participation of persons with disabilities*

Raising awareness

Everyone is busy with their daily tasks. There are deadlines from donors, new proposals to be written... So how to find time to work on commitment? And what kind of activities could you undertake to get commitment in your own organisation? And how to raise awareness amongst partner organisations?

Of course you will need to have a different approach for convincing board members and senior management to the one you use with programme and facilitating staff (for example, the communication, HRM and finance departments). At a board meeting you will probably only get one hour of the time available, while you might take a whole day with office staff. Whomever you approach, attitude change is the first step in getting commitment. Traditional viewpoints on disability need to be challenged and a rights-based view needs to be presented. How to do this?

If you are able to get one day of your colleagues' time, you could organise a workshop. *Travelling Together – how to include disabled people on the main road of development* is a one-day training programme developed by World Vision which will certainly help to create a sense of urgency in your organisation to be serious about the inclusion of persons with disabilities. There is a clear manual available with hand-outs and instructions for trainers. If you don't have a whole day, you could pick one or two of the exercises mentioned there. *The Game of Life*, a one-hour interactive exercise that visualises the discrimination persons with disabilities face, is very useful as a stand-alone activity.

→→ *An informal environment makes it easy to speak freely*

But there are also more informal ways to sensitise your colleagues about disability inclusion, say experienced campaigners on this issue.

'The most fruitful discussion on disability mainstreaming during these workshop days I had in the line in front of the ladies' toilet,' observes Saskia van Veen, researcher in the Thematic Learning Programme. 'I chatted with one of the participants and suddenly we got to the essence of practicing disability mainstreaming. This informal environment made it easy to speak freely, without strategic caution.'

'When I am travelling to our partner organisations in south Sudan,' adds Bertien Bos, programme coordinator at SeeYou Foundation, my schedule is often fully booked with official meetings. This means there is little time to discuss new ideas. At the same time, while visiting the projects we spend a lot of time on the road. After the usual "family chat" I introduced the issue of inclusion.'

'I organised a lunch meeting amongst colleagues to raise awareness for the inclusion of people with a disability,' relates Hendrien Maat, senior education specialist at Edukans. 'It wasn't

Tips for awareness-raising in your organisation

- **First focus on the people who are interested. They can help to convince the others.**
- **Form a team to raise awareness in the organisation.**
- **Keep it simple; no difficult and boring lectures.**
- **Focus on attitude change and try to touch people's hearts.**
- **Make meetings pleasant: do an interactive exercise, show a video and bring a home- baked chocolate cake.**
- **Prepare well; don't be surprised by critical comments.**
- **Involve a person with a disability as a (co-)trainer.**
- **Use informal moments as well**

especially focused on the issue of communication and fundraising, but this did become an issue as disability was seen as an opportunity for raising money. A second point that was raised in this respect was, "What does society get back for investing in people with a disability?"'

'Everybody who collaborates with us will be sensitised on inclusion of children with disabilities in education' warns Alebachew, executive director of the Basic Education Network, Ethiopia. 'Inclusion of the poorest of the poor is something we will bring in every time we can, and inclusive education for children with disabilities is part of this.'

'We wanted to raise awareness on our board about the importance of a rights-based approach towards disability,' recalls Paulien Bruijn, programme coordinator at SeeYou Foundation. 'We asked Yetnebersh Nigussie, programme coordinator of ECDD, who has a visual impairment herself, to host the session. She showed an awareness video and did an interactive exercise. The presentation was a big success; the board members looked really touched. Later on during the evening the board members had to decide on our new policy on the rights-based approach and disability mainstreaming. The documents were accepted without any hesitation.'

Embedding disability inclusion in organisational strategies and systems

To create sustained change, inclusion of persons with disabilities should be embedded in the policies, systems and structures of the organisation. In this chapter we will explain how.

Policy development

→ *There's no one correct way – it depends on the organisation*

Organisations often don't know when they should start writing a policy on inclusion of persons with disabilities. Do we start the process with writing a policy or do we just begin our process and write a policy at the end? There is no single correct answer here because organisations are very different. In some organisations, policy documents are very important; in other organisations they are not. If, in your organisation, nothing is going to happen if it is not written down in a policy, you definitely have to start with including disability in the policies. But if your organisation is more focussed on learning by doing, it may be better to start experimenting and start writing a policy when the process is underway.

Beware of writing policy documents before there is real commitment from management. Policy documents are not tools for raising awareness and getting commitment. There's a big chance that your nice document will end up in a drawer

if the vision is not shared and agreed upon beforehand. Ideally, policy development is a creative, bottom-up process with a clear link to practice. So if there is no full commitment in your organisation yet, you had better start working on good practices. Don't wait until there is an organisational policy. Our experience is that many steps can be taken without a policy. If there is enough commitment you can begin to define a policy on disability-inclusive development.

Step 1: draw up an inclusive statement on disability

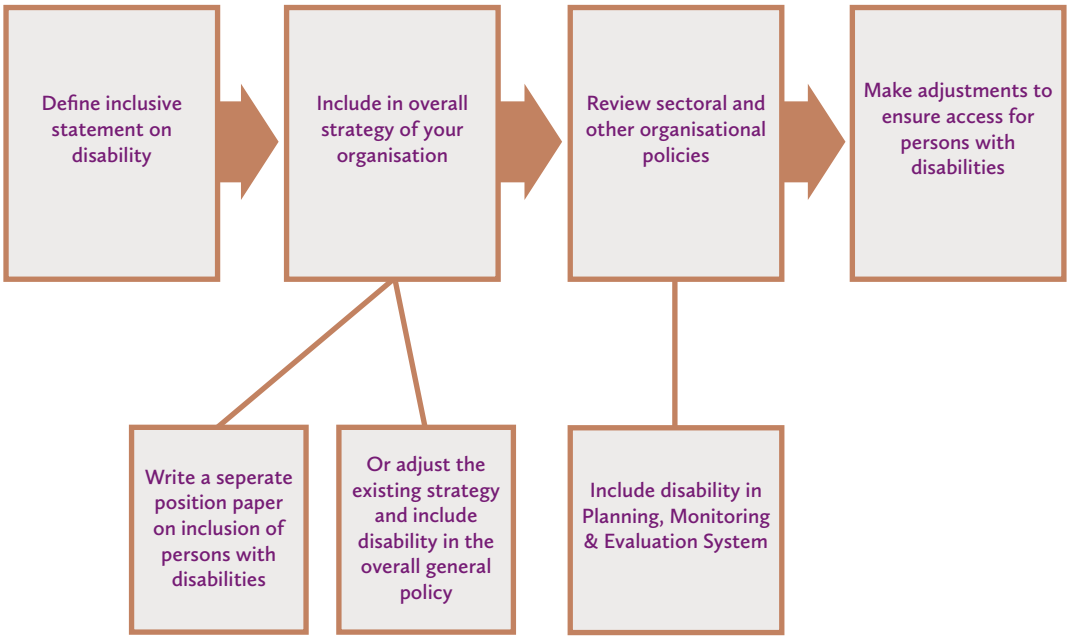
This starts with defining what disability means to your organisation. It will give an idea of the scope and direction of the policy to be developed. It is important here to answer the question of why your organisation wants to include persons with disabilities and how this links to the core strategy of the organisation. Is inclusion of persons with disabilities part of reaching out to marginalised groups? Or does it link to the rights-based approach of your organisation? Once these questions are settled, Step 2 can be taken.

Example: Tear Netherlands' inclusive statement

'Tear works within a worldwide network of local churches and Christians who are committed to combating the causes and consequences of poverty and the injustice associated with this, and working on the restoration of relationships and just relations... Inclusion of people with a disability fits within this vision. It corresponds to the overarching principle Tear wants to convey, focusing on value-driven development, every person is precious, equal opportunities and rights for all. Inclusion of people with disabilities matches with the attention to marginalised groups in society and tapping into the strengths and capabilities of these people. Often poverty, injustice and disability reinforce each other in a negative way. Most of the people with disabilities in developing countries live in poverty and face an unjust situation. By aiming at an inclusive society for all, Tear intends to improve the living circumstances of this specific group.'

← *If there is not yet full commitment, start working on good practices*

↑ *Combating the causes and consequences of poverty and injustice*



→ *Including the issue in general policy is more sustainable, but writing a separate position paper can be a practical solution.*

→→ *Make budget allocations for creating access*

→ *Work out the practical implications for sectoral policies*

Step 2: include disability in the overall strategy of your organisation

Here you can follow one of two strategies: write a separate policy document on the inclusion of persons with disabilities or include the issue in your organisation's overall strategy document. The latter option will be more sustainable, but might not always be possible. Organisational policies can be very static, so you may have to settle for a separate policy document and wait until the next round of policy revision.
Tear Netherlands has made disability a crosscutting issue for their organisation and included disability in their overall programme policy. They also developed a set of rules to be applied during assessments and monitoring of projects.

Step 3: review sectoral and other organisational policies

When the overarching policy is formulated, it is also advisable to look at the practical implications in sectoral policies. So if you have a sectoral policy on education, work out what it means to include children with disabilities. If you have a policy on reproductive health and rights, describe how you want to ensure equal access for persons with disabilities. It is also good to look at other organisational policies, such as the human-resource management policy, communication and fundraising and capacity-building. For each of these policies, concrete implications of the inclusion of people with a disability can be formulated.

Step 4: make adjustments to ensure access for persons with disabilities

The key issue in disability-inclusive policies is to make sure that persons with disabilities get access to your projects and organisation. This can only be achieved if barriers are removed and necessary adjustments and modifications are made. These adjustments can be the provision of information in an accessible format, such as Braille or special computer software, or the construction of a ramp to make your office accessible to wheelchair users. You need to budget for these adjustments.

Disability-inclusive human-resource management

To create sustained change, inclusion of persons with disabilities should be embedded in the policies, systems and structures of the organisation. In this chapter we will explain how.

Hiring persons with disabilities in our own workforce is not usually the first step we take when we start working on disability-inclusive development. This is a great pity. There are three reasons to give this priority. [1]

- We get much more credibility as a development organisation if we practice what we preach. We all agree that organisations that strive for equal rights and participation of women should look at the representation of women in their own workforce and management. The same applies to persons with disabilities.
- If your own organisation is able to successfully include persons with disabilities in the workforce, this says more than a thousand words. It is a very strong way to raise awareness about inclusion within and outside your own organisation.
- Making the organisation accessible to persons with disabilities is a good learning process. It will sensitise staff to the needs of persons with disabilities and how to address these needs. It forces your organisation to remove barriers and welcome persons with disabilities. This experience will help your organisation to make its programmes inclusive as well.

'One of my colleagues uses an electric wheelchair,' notes Paulien Bruijn of SeeYou Foundation. 'When she started working here, the organisations in our network didn't think about accessibility at meetings and conferences. But one day she registered for a meeting and found

out that it would be held on the third floor. There were no elevators so she couldn't participate. This made the colleague organisation aware of the need to organise meetings at accessible locations. Now they really try to make sure meetings are accessible.'

→→ *Remove barriers*

How to make HR policies and practice inclusive

→ *Include disability in your diversity policy*

Specifically include disability in the existing staff diversity policy. If you would like to set a quota, you can use the percentage advised by your government (in the Netherlands this is 2% for organisations with more than 100 employees; in India it is 3%). But of course you're always free to set a more ambitious quota.

Take affirmative actions like placing job announcements in disability networks or mention specifically that you are inviting persons with disabilities to apply.

Remove the barriers that staff with disabilities will face while doing their work: maybe some extra budget is needed for transport or screen-reading software or maybe the office and toilets have to be made accessible. Check whether there are government subsidies available for making the workplace accessible.

Including disability in the planning, monitoring and evaluation system

To create sustained change, inclusion of persons with disabilities should be embedded in the policies, systems and structures of the organisation. In this chapter we will explain how.

Embedding disability in your planning, monitoring and evaluation (PME) systems ensures structural attention to the issue. It also provides valuable information that can be used to improve the inclusion of persons with disabilities in your programmes and explain to donors that inclusion is relevant, effective and efficient.

The systems that development organisations have for planning, monitoring and evaluation are very diverse, so it is difficult to lay down universal steps on how disability can be included. But here are some suggestions.

Include a disability perspective in the existing formats. Think of baselines, proposals, reporting formats, project-visit formats, evaluations reports and annual reports. There is no need to develop a parallel system to monitor inclusion of persons with a disability. Even if your organisation has not yet started systematic disability mainstreaming in its programmes, you can start including disability data in the

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Include a disability perspective in existing formats

monitoring and evaluation system. This will give you insight into what is already happening in your programmes. If you work with partner organisations that implement programmes, including a disability component in the formats is a good way to start the conversation about inclusion of persons with disabilities. There's a big chance you will be inspired by the feedback.

Project proposals or concept notes should clearly state how the programme is of relevance to persons with disabilities and their families. They should also state what measures will be taken to ensure persons with disabilities benefit in equal measure to others in the target group. If you are writing a proposal for a donor who does not specifically ask for inclusion of persons with a disability, still include the disability dimension. You can probably include it in the section 'reaching out to marginalised groups'.

→ *No need for specific targets or indicators*

There is often no need to develop specific targets or indicators on inclusion of persons with disabilities: just start by collecting disability disaggregated data. So add a disability component to the existing indicators, just as you do with gender. When you ask how many men and how many women are benefitting, also ask how many men and women with disabilities are benefitting.

It is important when you collect data about disability to disaggregate for gender as well, because women with disabilities face a double burden. They are less likely to participate in development programmes than men with disabilities.

→ *Just collect disability disaggregated data*

It is advised to allocate a specific budget for removing barriers in the programmes. 2-7% is usually enough to cover these costs.

→ *Evaluate the quality and impact the programme has on the lives of people with disabilities*

Field visits are an excellent opportunity to discuss the inclusion and participation of people with disabilities in programme activities, achievements that have been made and challenges faced. During project evaluation, you need to review the participation of people with disabilities. Terms of reference should include evaluation questions about the participation of persons with disabilities in the programme, not only about numbers of people who benefit and participate (according to gender, age and impairment), but also about the quality and impact the programme has on their lives. Also focus on what measures have been taken to remove barriers in the programme. This will help you to improve access for persons with disabilities in the future.

Organisations often collect life stories of participants to present the achievements of their programme to a wider public. Also collect life stories of persons with disabilities who participate in the programme. Present them as equal participants of the programme and activities. Try to avoid portraying them as pitiful or as heroes, people who are exceptional.

Creating access to facilities and information in your own organisation

‘When Shitaye, from the Ethiopian Center for Disability in Development, came to us to do the intake assessment, the inaccessibility of our office became very clear,’ recalls Addise Amado, Programme Manager, EKHC Water and Sanitation programme. ‘She could not enter with her wheelchair, so we had a meeting on our parking lot. This really shocked me. I felt very sorry about that. We are currently renovating the pavements. However, the installation of lifts is a big challenge in an old office building. But we have the commitment of our General Secretary, a Structural Engineer by profession, to correct the past mistakes in the infrastructure.’

Checking the accessibility of your organisation

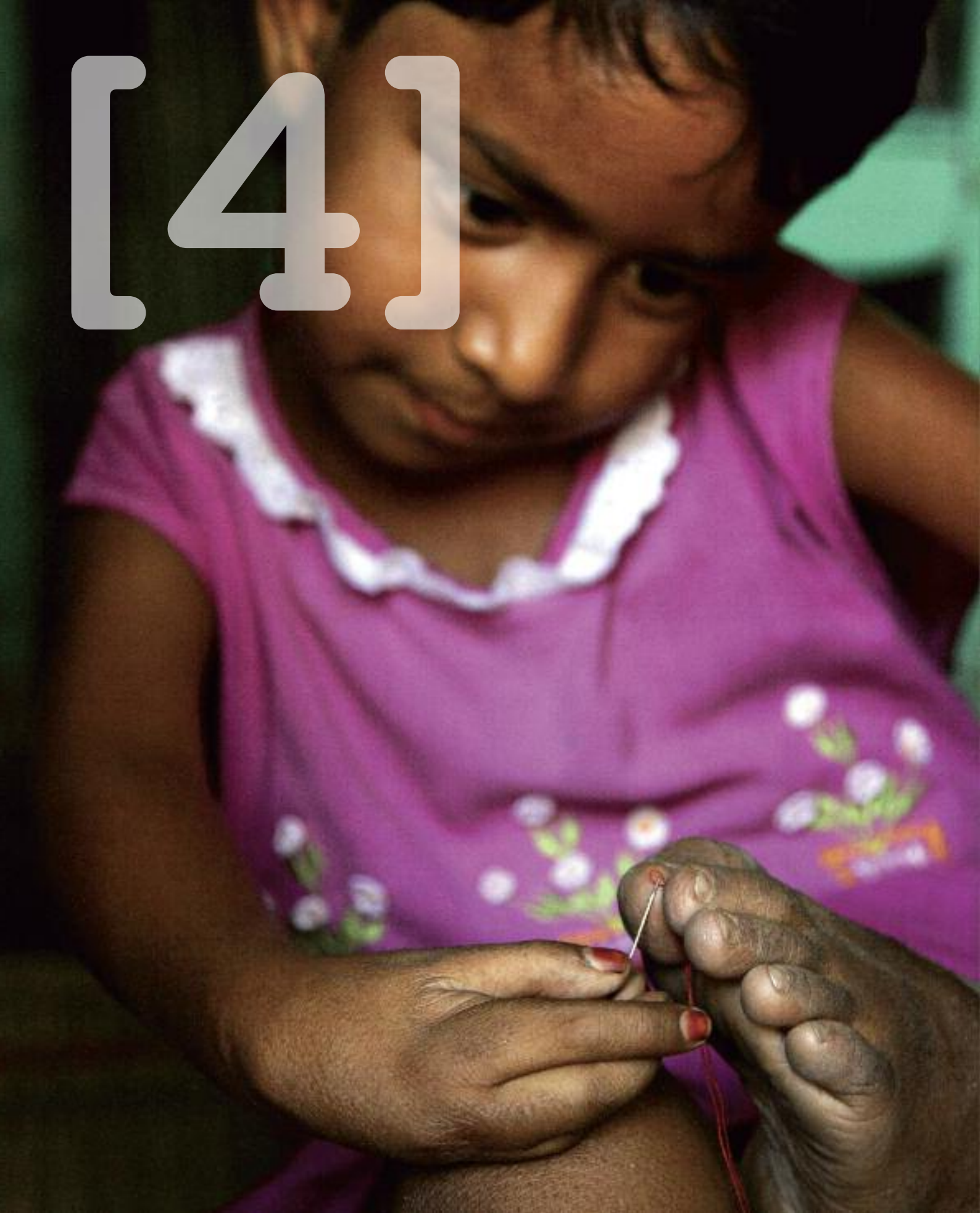
topic	goal	remarks	resources
Physical accessibility of meeting rooms, toilets, work places.	The whole office, including all work places, meeting rooms and toilets are accessible to persons with a disability.	Make sure that at least the meeting rooms and toilets are accessible. If you have staff with disabilities, (most of) the work place should be accessible.	Website CBM guidelines on accessibility: http://www.cbm.org/article/downloads/54741/CBM_Accessibility_Manual.pdf Ask a person using a wheelchair to do a check of the premises.
Accessibility of events organised by your organisation: conferences, training events, concerts, sponsored walks and so on.	All events organised by the organisation are accessible to persons with disabilities. Communicate that the events are accessible and ask participants if they have special needs.	If one of your events cannot be made accessible, communicate clearly how accessible it is (or not). Invite participants to reveal their special needs and try to find ad hoc solutions.	See above.
Accessibility to the website and other information sources of the organisation for persons with visual impairments.	Website is fully accessible and newsletters/brochures are available in accessible formats.	Concerning accessible information: for visually impaired people using computers, a digital version in Word is often enough. PDFs are more difficult to navigate for speech software. Communicate that you can provide Braille print on demand.	Do a Bobby-proof check of your website: Bobby is a free public service to make the internet more accessible to individuals with disabilities: http://www.cast.org/learningtools/Bobby/index.html Ask your local association of the blind where to obtain Braille print services.
Accessibility for persons with hearing impairments.	Sign language interpretation is always available as an option.	Communicate that you are willing to provide sign language if people ask for it.	Collaborate with your local association for the deaf.

Here we will focus on removing the environmental barriers in your organisation that prevent persons with disabilities from participation.

There is more to consider than the physical accessibility of your offices. You also need to think of accessibility at conferences, meetings and more social events, such as sponsored walks or concerts. Last but not least, there is also the issue of accessibility of information.

The CBM guideline on accessibility gives hints on how to improve on weak areas. But a much easier way to make your organisation accessible is to ask people with various types of disabilities to do an accessibility audit: visit your offices, facilities and services and use an existing accessibility audit form to identify what changes are required within your organisation for it to become more inclusive to all.

Shitaye at a training session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Concluding remarks: lessons learned

It has been a great adventure to work on this subject with over 30 development organisations on three continents. Our journey towards inclusion of persons with disabilities has been an inspiring one. In these three years we have collected a suitcase full of experiences, lessons learned and tools. We have tried to bring all these experiences together in this guide. In this last chapter we'll attempt to summarise the most important lessons that we have learnt from this journey. This is not an easy task. There are so many things that we have seen and each person and organisation draws its own unique lessons.

Everything starts with attitude change

Everything starts with attitude change: that's the first important lesson. Persons with disabilities can only be welcomed and included in our projects and organisations if we really believe in their capabilities. I'll never forget the personal story of Kumar, a young man from South India:

'Life was good for me, until I was hit by a car when I was in grade ten. They rushed me to the hospital, but the doctors couldn't do much for me. I returned home a paraplegic. I was lying in bed for years, day and night, without any hope, without any treatment. My parents were desperate, but really tried to take care of me. I got so frustrated that I wanted to kill myself. But that's not easy when you can't move your arms and legs. Someone gave me a Bible. After reading that I didn't want to die any more. Soon after that I met someone from a self-help group. The people from the group came to my house to help me with exercises. After two years I was able to sit in a wheelchair. I learned how to dress and wash myself and also how to write again. When I got to that stage, I also wanted to find a job. My family laughed at me, but I persisted. I started a telephone booth. The customers dialled their own numbers and took their change while I was looking. Business went well and I bought some computers to start a computer-training centre. I now employ four staff members. The nice thing is that I don't have to ask my parents for money; now they come to me!'

When I asked him what development organisations could do for persons with disabilities, Kumar said: *'It is not enough to give a wheelchair or a crutch. Persons with disabilities need self-confidence; they should realise that they can do it themselves. We don't want your pity, just tell us: "You can do it!"'*

No pity, just an equal chance and a bit of encouragement. That's what inclusive development is all about. Awareness training for staff and management is essential to reach this change of attitude. Our experience is that the most effective way to create awareness is to involve persons with disabilities as trainers.

Quick results are possible, but a long breath is needed

Once programme staff is aware of the capabilities, needs and rights of persons with disabilities, it is often not difficult for them to open up their projects to disabled persons. Budget is not a big problem. Inclusion does not cost too much if you incorporate it into existing structures and activities.

For example, the WASH programme in Ethiopia: after awareness training, the staff started training community groups about disability rights. As a result of that, some people with disabilities were enrolled in the water committees and one person with a disability was appointed as a water-point caretaker. This was an activity that did not involve any extra costs because the fieldworkers would go for training anyway.

Also schools can relatively easily identify and enrol children with disabilities without much extra cost. However, it is important to realise that inclusion is a process. There are different levels. It starts with presence. The second level is participation. The last stage is achievement. We should not be happy with presence only, but strive for participation and achievement.
Along the road, we discovered that inclusion of persons with disabilities can only be reached if disability-specific service providers, the government, disabled people's organisations and mainstream organisations work closely together.

After the WASH programme in Ethiopia raised awareness in the community, disabled people started asking for wheelchairs and medical treatment. They decided to link up with disability service providers to refer persons with disabilities for assistive devices and medical treatment. Mainstream organisations don't need to become disability-specific service providers; they only need to open up their programmes to persons with disabilities and should refer them for disability-specific interventions if these are necessary.

Organisational change takes time

Another important lesson from the Thematic Learning Programme is that it takes time before organisations are willing and able to fully commit to the inclusion of persons with disabilities. The management needs to feel the urgency to end exclusion. Additionally, commitment from programme and support staff is needed. There can be a lot of resistance so it is essential to spend a lot of time on raising the awareness of management and staff. In this Thematic Learning Programme, we chose to train focal persons to stimulate and oversee the change process within their organisations.

Starting with pilot projects works well for many organisations. It doesn't require any adjustments in policies and systems and you don't need the full commitment of your board or management. Besides this, it is a great learning ground for the organization. Many start with pilot projects and then use their experience to anchor the topic within their organizational structures. The best way to convince senior management about the inclusion of persons with disabilities is a successful project where people with disabilities are included.

Our conclusion is that organisations can successfully include persons with disabilities in their projects without having any kind of policy. But if they really want sustainable change, disability eventually needs to be incorporated into systems, policies and structures. Organisations are often reluctant to include persons with disabilities because they see it as an additional issue to be dealt with. Linking it to the core mission of the organisation is a good way to deal with this.

Good company makes the journey easier

The road towards inclusion of persons with disabilities in mainstream development is relatively new. So it was a great experience to travel together. The Thematic Learning Programme really was a unique chance to share and learn together and to motivate each other to persevere.

The funding for the learning platform has come to an end, but we have a strong basis to continue our cooperation and network. We realise that the journey has only just begun and that there are many more adventures ahead of us. If you are interested in joining our network, please contact us at SeeYou Foundation: info@seeyoufoundation.nl.

Endnotes

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1. Dfid (2002)

Page 18
2. http://www.making-prsp-inclusive.org/en/6-disability/61-what-is-disability/611-the-four-models.html

Page 26
3. S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999

Page 67
4. http://www.mindtools.com/pages/article/newPPM_82.htm

Page 73
5. S. Miles, Strengthening Disability and Development Work, BOND Discussion Paper, Feb. 1999

The learning continues

Please check our website for the latest information about our new training & learning programmes. You can also subscribe for our newsletter, browse through our resources on disability mainstreaming, or download the English, French or Word version of Count me in.

Website: www.seeyoufoundation.nl/en

Colophon

Count me in
Include people with disabilities in development projects
A practical guide for organisations in North and South
By Paulien Bruijn, Huib Cornielje, Niala Maharaj,
Barbara Regeer, Saskia van Veen and Roelie Wolting

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For more information check:
http://www.seeyoufoundation.nl/en/
or write to: info@seeyoufoundation.nl

People with disabilities are often amongst the poorest in the developing world. Yet they are usually left out of development projects. This is not because of ill-will. Development organisations simply do not know how to include them. This book offers suggestions based on the experience of organisations that participated in a two-year learning programme. It is full of useful tips on how to launch inclusive programmes and projects, how to prepare your staff for working with people with disabilities and how to adapt your organisational processes and systems.

count me in

The following organisations have contributed to this publication:

see you including everybody

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