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Travelling together

**HOW TO INCLUDE DISABLED PEOPLE ON
THE MAIN ROAD OF DEVELOPMENT**

Sue Coe and Lorraine Wapling

ONE WAY ONLY — NO RETURN — ONE WAY ONLY



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Sub-edited by Clive Price.

Clive Price is an award-winning author, popular publicity writer and qualified journalist. He assists a number of leading charities and organisations with their public relations work, and has contributed to newspapers and magazines in the UK, Ireland, Australia and the USA. Clive has worked with World Vision on a number of projects, including writing *The Hands and Feet Of Jesus*

Contact: office@cliveprice.com

Designed by Dodo, Mammoth, Reindeer & Fox.

www.dodomammoth.co.uk

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THE MAIN ROAD OF DEVELOPMENT

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About the authors



Sue Coe is Senior Disability Programme Adviser at World Vision UK. She has worked in wide-ranging roles in international NGOs for 20 years (ITDG – now Practical Action, VSO, World Vision) and managed RNID's Sign Language Training Programme in the UK for 2 years. Sue has an MSc in International Development Management (Open University, UK) and an MA in Philosophy, Politics and Economics (Oxford University).

Contact: sue.coe@worldvision.org.uk



Lorraine Wapling is a freelance development consultant providing training and project-based support to a range of international NGOs and donor agencies on the inclusion of disabled people as well as working directly with Disabled People's Organisations in developing countries. She has extensive research and development experience in Africa and Asia, gained over 15 years in sectors ranging from education to community development. Lorraine is also an Associate Adviser to the Kesho Trust, an international organisation focusing on promoting community-led development that protects and enhances the environment. Lorraine is herself profoundly deaf.

Contact: consultant@wapling.me.uk

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Most of all, our thanks go to all the many people we have encountered over the past 15 years across the world who have inspired us to see this project through to completion. Our shared desire is to see the inclusion of disabled children and adults in international development become an authentic reality.

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Foreword

Charles Badenoch

Vice President,
Advocacy and
Justice for Children,
World Vision
International



I was at a school for deaf children in Burma. Yet I was alone. Everyone in the room was able to communicate with sign language – except me.

It was a brief glimpse of what it's like to be the so-called 'disabled minority' in the so-called 'non-disabled majority'. But there was a key difference here. All the children wanted to include me. They wanted to teach me sign language.

That was one of my first trips with World Vision, the agency I serve. But it wasn't just experience that made me start to fight for the rights of disabled people. The facts and figures of injustice also convinced me. Here are a few:

- 98 per cent of disabled children in developing countries don't attend school;
- disabled children are more likely to experience violence from birth;
- the mortality ratio for disabled children may be as high as 80 per cent in countries where under five mortality for other children has fallen to 20 per cent;
- only two per cent of disabled people in developing countries have access to basic services.

I realised that in the wider development community, we couldn't be true to our vision if we didn't include all disabled people in all our work. That's where this course came in. Developed by World Vision UK during my tenure as Chief Executive, the programme aimed to equip staff through an accessible, interactive training day packed with practical activities.

Participants were encouraged to understand and identify their attitudes towards disability. This is critical for all of us who seek to include disabled people in our work across the board. The global disability movement has consistently identified negative attitudes as the main barrier to their inclusion in society. This course directly addresses that.

Since its first delivery in June 2006, the training has been delivered to more than 1,800 of our staff and partners in 21 countries across five continents. Our largest National Offices have requested and received training.

Part or all of the course has also been delivered to more than 600 people in governments, NGOs and Disabled People's Organisations (DPOs). I was present on two of those occasions – at the BOND Disability and Development Group event in London, December 2007, when senior people from the UK development sector marked the International Day of Disabled People – and during the Disasters Emergency Committee Trustees meeting in Spring 2008, with the Chief Executives of all member agencies.

One common theme runs through feedback from each training day – IT WORKS – in every geographical context and at every operational level. Disabled people report transformation of how they perceive themselves. In Angola, two visually impaired people said, *“You mean we are not the problem?”*

But don't just take my word for it, see the words from colleagues in India and Ethiopia...



Jayakumar Christian, National Director, World Vision India

“Disability inclusion is an important issue for World Vision India. We see it as a reflection of World Vision India's commitment to serve the marginalised in our society. Many of our colleagues have approached disability issues in our communities with a charity or medical perspective, the social model has been mind-opening.

The training has been very helpful. We now understand disability according to the social model and rights-based approach. The biggest impact of the training is how we diagnose the issue – the problem is society's to include children and adults with disabilities rather than looking at the impairment of the person as the problem. The terminology used by our trained staff for people with disabilities with different types of impairments has also changed.

The training has brought about changes in our approaches to engaging disabled children and adults in our communities. Trained staff have been intentional in bringing disabled children to participate actively in project activities and mobilizing the communities to involve disabled people in the community decision-making process.”

Lydia Mesfin, Advocacy Manager, World Vision Ethiopia

“In Ethiopia, disability issues have been invisible in economic, social and political agendas. This was also the case in World Vision Ethiopia. Disabled people are the poorest of the poor in the country and marginalised because of misconceptions about disability. World Vision Ethiopia is known for its developmental work through the country but until very recently it was not inclusive of disabled people, even though they account for significant numbers in the population. Excluding disabled people was not intentional on our part but this course helped bring the realisation to staff that we need to engage in disability issues.



The training involves a range of methods which were interactive and very engaging. The excitement of the participants during courses was visible. The commitment of the senior management team of World Vision Ethiopia to take up this issue was evident following their training course. The participation and commitment of trainees to attend all days was historical when you consider their busy schedules! The professionalism of the trainers was very impressive. Above all the simple techniques and uncomplicated messages were very impressive – it helped us understand disability inclusion and own it.

What we have learned most in World Vision Ethiopia from the feedback of all the training we have conducted is that all rests on our attitudes and the first step to inclusive development is to change our attitude towards disability. The training has forced us to look at ourselves and seek the solution within. It has also helped World Vision Ethiopia establish relationships and network with Disabled People's Organisations and Government sector offices on this important issue.”

We've not yet achieved full disability inclusion at World Vision. We've not yet got it right. But we're beginning to build foundations. We hope within the next few years we'll have mainstreamed disability throughout our organisation. This course is an essential tool towards that aim.

What we've come to realise is that this isn't about a sectoral priority. It's about inclusion. We cannot see 20 per cent of people living in every community we work in across the world as 'just another sector'. We must move beyond the 'viable poor' and include the poorest of the poor. It's

a justice issue. It's also a fundamental issue of logic. We're never going to reach the bottom billion if we don't include disabled people.

So I'm delighted to be recommending the training course and other materials in this book. I hope you find them interesting. More importantly, I hope you'll use them to include disabled children and adults in your work.

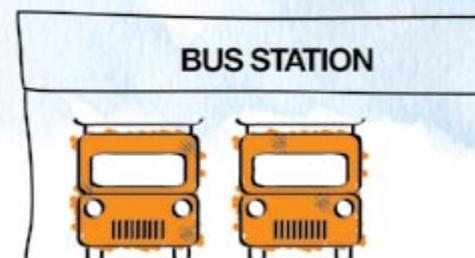
Read, use and enjoy!

Introduction

Only two per cent of disabled people in developing countries have access to basic services and rehabilitation



Travel plans



THERE ARE THREE KEY SECTIONS

activities and handouts –

first of all, you'll find a whole host of fun and thought-provoking training activities. For each activity there is an explanation, outline and – where referred to – handout.

stories from the road –

second, we'll tell you the story behind the course, offering you and your team further insights into how and why this course was designed, and its impact so far.

resources –

third, you'll discover a wide range of resource materials to take you and your team deeper into the issues raised.

Take a day to make a change. That's all we ask.

By picking up and using this book, you can start a process of transformation within your work – to bring about positive change for disabled people in the communities you work with.

And all you need is a day. It's as easy as that.

Interested?

If so, this book is just for you. It has been designed as a simple, interactive tool to offer confidence and understanding to your programme staff as they seek to bring disabled people onto the main road of development.

Just follow these ten easy steps. Start a journey that will offer great benefits to you and the communities you work with:

- 1 take a little time to read through the book;
- 2 familiarise yourselves with the main ideas;
- 3 plan a day of training, thinking about how much time you have and who you can involve (we have made some suggestions for you in the activities section);
- 4 invite the whole team – we find it works best if managers and field workers are all involved;
- 5 follow the activity plan, use the handouts provided – and have fun;
- 6 invite feedback and evaluation (see Activity 8 on pages 35–36 for ideas on this);
- 7 a week or so later, ask people how the day has altered the way they approach their work;
- 8 keep the process of transformation under review;
- 9 keep a journal of your progress;
- 10 please tell us (the authors) and World Vision how you get on – your reflections may help future editions.



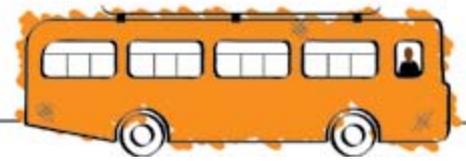
You and your team should have an enjoyable and enlightening experience as you use this tried and tested course. And while there are plenty of practical ideas for including disabled people in your development work, remember a change of heart and mind is the most important thing that could happen within you and those you train.

Everything else will spring from that.

There's a crisis of confidence within the development community across the globe. It's a crisis of confidence in actively including disabled people. But it's a crisis that can be overcome.

And this is the place to start your journey...

Get equipped



The aim of this course is to help you to bring about positive change for disabled people in communities where you work. To break down barriers between disabled and non-disabled people. The course is:

- designed to boost disability inclusion in development programmes;
- developed primarily for programming staff who have not considered disability inclusion before.

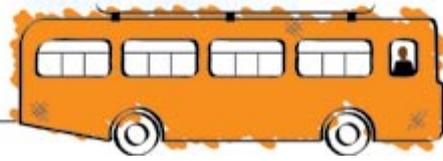
Ideally, this workshop should run over a full day and we have provided you with a sample programme in this section. But any of the sessions can be used as stand-alone activities if there's limited time. Most popular activities to use in this way are: **Guessing Game, Defining Disability** and **Game of Life**.

Each activity raises important issues and can be effective in initiating interest in disability inclusion. You can also combine any sessions into a new format depending on time available. But we've given you what we've found to be the most effective order. The reasons behind each activity are described in the 'Motive' sections which will help you keep things focused in the training room.

If you're a mainstream organisation keen to become more inclusive, one of the best ways to conduct this training is with disabled people. Ideally, this training should be led by disabled people. But if you're not well connected to local disability groups (Disabled People's Organisations – DPOs), it's still possible to run the training programme yourselves. Use this training as a way to start making links with disabled people and finding out what the situation is like for them. Invite them to come and take part.

The selection of the training room and its layout is important. There needs to be suitable space for group working and displaying materials. Place participants in a 'horseshoe' shape where possible, rather than having 'formal' rows and lots of tables. A light and bright environment is helpful. It doesn't send out the right messages if you choose a room which disabled participants cannot access, and/or which does not have suitable toilet facilities.

Any of the sessions can be used as stand-alone activities or you can create your own combination of sessions depending on how much time you have available.

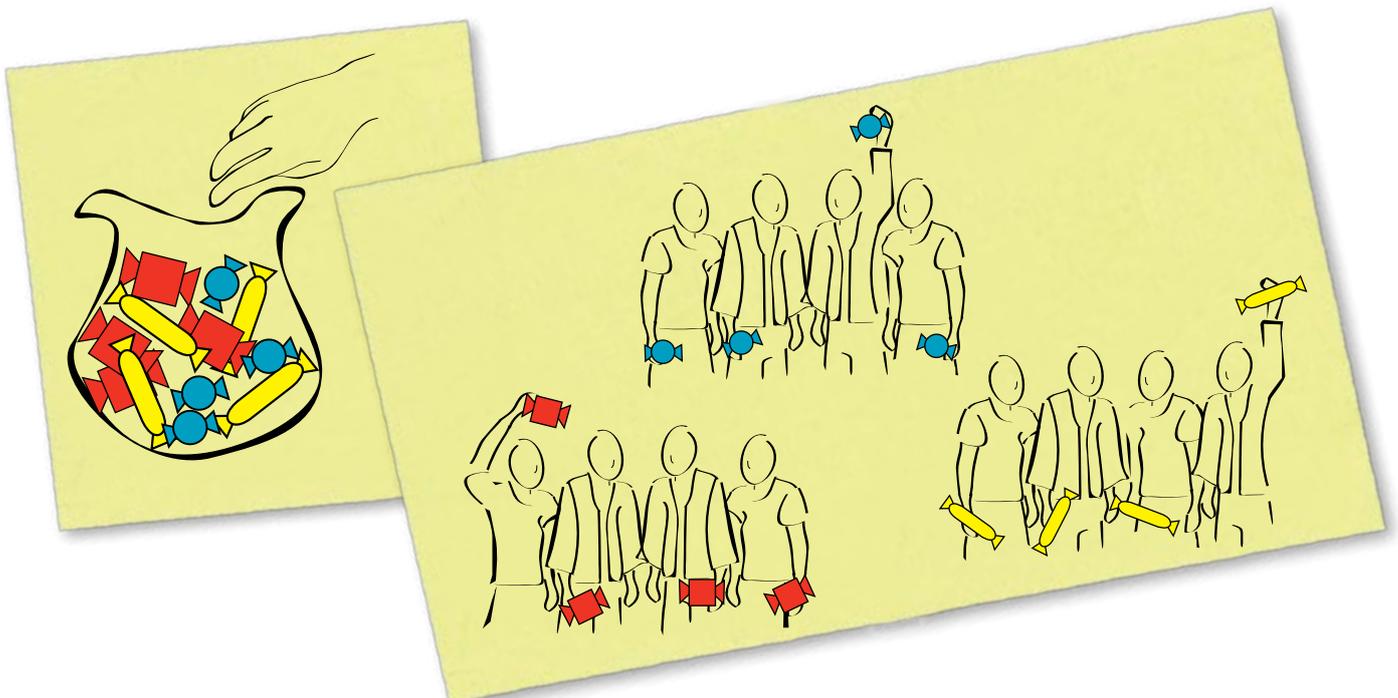


PRACTICAL TIP

Give folders to participants with name labels (or blank labels to write their names on) to place photocopies into – it keeps everything together so participants leave with the right materials!

Make sure you are well prepared. Use the activities and handout sections to prepare yourself for the training day. Make sure you have enough post-it notes, cards, flip chart paper and pens to cover all the activities. Prepare displays ahead of time. Have enough copies of activities and handouts to give to each participant – it is their training record and prevents them having to take extensive notes. You can either give them out at the end of each session (so they build a portfolio during the day) or as a complete set at the end of the day. You may also want to give them soft copy versions (CD or memory stick) for ease of reproduction later.

Throughout the day there is a range of group work. Think about how you want the groups to be divided. If randomly, then try using wrapped sweets (chocolate, toffee, boiled etc.) making sure that each type has a different style/colour of wrapper. You'll need the same number of types of sweets as you want groups, then the number of each type of sweet as the number of people in each group. Mix all the sweets up, then hand around the group, asking them to take a sweet from the bag(s). Their group is the other people who have the same type of sweet as them! People appreciate sweets – small chocolate bars from the UK are especially popular – and as trainers the 'sugar rush' of the sweets can help lift the energy in the room!



HOW TO CREATE AN INCLUSIVE TRAINING ROOM ENVIRONMENT FOR DISABLED PEOPLE

As you organise your course on inclusion, ensure disabled people can participate. Here are a few key principles to bear in mind:

- be prepared for disabled participants even if you haven't specifically invited them;
- try to know your audience in advance by asking all participants if they have any access needs in the invitation. That way you can prepare your venue and materials to take account of their impairments;
- think about access at an early stage so you have sufficient funds set aside to cover adjustment costs.

Even if you ask people to inform you ahead of time sometimes disabled people will arrive without you having anticipated it. So check access issues before starting on the day. The simplest way is to ensure everyone is greeted on arrival - either by the facilitator or their assistants.

Mobility – think about any activities you're planning to use that rely on moving around quickly and/or a lot. Consider how someone with a physical or visual impairment might be excluded from this activity.

Usually, you'll be able to find ways of adjusting activities with a little creativity. If you have time during your preparations consider asking people with mobility impairments how they could participate in your planned activity. If this isn't possible, be prepared to change the activity for something less physical. The important thing is to ensure everyone is included and can participate.

Sight – if people with visual impairments are attending, there are a number of protocols to follow. Take them around the workshop venue and facilities (including the toilets!) at the beginning of the day, to familiarise them with the layout.

Ask people to state their names before talking in any discussion so everyone knows who is speaking. At the beginning of any session when people may have changed places, going around the group and asking



people to give their name helps visually impaired people to know who is present and where they are located.

Remember to describe any visual aids used in the course of the workshop such as PowerPoint demonstrations, drawings, posters, flip charts, handouts, etc. Read out loud what is written. This also helps people with limited literacy skills.

If there are any practical exercises, ensure anyone with a visual impairment is able to feel and touch the exhibits. Simple charts, diagrams, drawings and maps can be made tactile by glueing string around the outlines (in advance!). For people with low vision, large print versions of handouts are helpful as is making sure the room is well lit.

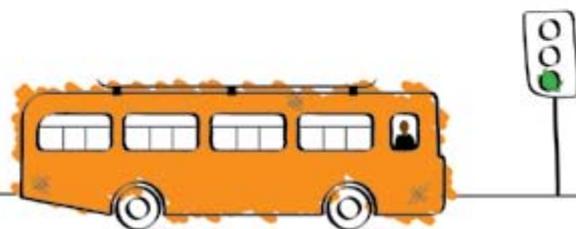
Hearing – if there are people with hearing impairments attending, find out their preferred form of communication – for example, sign language, or lip-reading?

For communicating with people who lip-read, ensure the speaker's face is well lit, and can be clearly seen by the lip-reader, and that they speak clearly without exaggeration. If the person uses sign language find out which interpreters are appropriate. There are often regional variations or the person may rely more on 'home signs' rather than a standardized form of sign language. Professional interpreters or communication support can be arranged through local deaf associations or in consultation with the deaf person and their family.

Frequent use of drawings and the written word are often helpful in supporting the inclusion of deaf participants but do not assume they can read as many will not have attended school.

Understanding – it's important to ensure that people with mild to moderate intellectual impairments are also included in community programmes. Their ability to understand information will vary according to the degree of impairment. The key is simple language, short messages, patience and repetition as necessary.

Timetable



SESSION 1 09.30 - 09.50

Introductions (10 mins)

Overview (10 mins)

This session will outline the purpose of the day, provide participants with the context – and ensure everyone is familiar with each other.

SESSION 2 09.50 – 11.00

ACTIVITY 1: **Guessing game** (10 mins)

ACTIVITY 2: **Defining disability**
(60 mins)

Challenging perceptions is this session's aim, which offers the opportunity to learn about disability as a human rights concept. It introduces models of disability and allows people to question their current views.

BREAK (15 mins)

SESSION 3 11.15 – 12.30

ACTIVITY 3: **The wall** (60 mins)

Reflection on the morning (15 mins)

How do disabled people experience society? Different barriers will be discussed and common mechanisms of social exclusion will emerge. The final part is a reflection on previous activities and a chance to discuss questions.

LUNCH (60 mins)

SESSION 4 13.30 – 14.30

ACTIVITY 4: **Game of life** (60 mins)

Why is it important to include disabled people in mainstream development work? This session aims to show how disadvantaged they are – and how development work can actually make their situation worse.

SESSION 5 14.30 – 15.00

ACTIVITY 5: **Unmasking myths** (30 mins)

Causes of impairments aren't crucial to mainstreaming disability. But it's important to understand what communities feel about them. Disabled people are often excluded because there are many myths about them. Unmasking those myths can help disabled people, their families and communities.

BREAK (15 mins)

SESSION 6 15.15 – 16.15

ACTIVITY 6: **Reality check** (60 mins)

Here is a window on how disabled people are influencing communities, service providers and governments for inclusion. Local representatives from the disability movement will make a short presentation and answer questions.

Or:

ACTIVITY 7: **Excuses excuses**
(60 mins)

Why has most development excluded disabled people? How can this change? This session will explore those questions – and introduce key concepts related to Disabled People's Organisations and their role in lobbying for inclusion.

SESSION 7 16.15 – 16.30

ACTIVITY 8: **Feedback forum** (15 mins)

At the end of the training programme, participants can reflect on the day's experiences. There will also be a chance to ask any remaining questions.

OBJECTIVES

- to show why disability is a development issue
- to demonstrate how attitudes make a difference
- to provide a range of tools for ongoing use
- to create a non-judgemental environment

ITEMS COVERED

- individual versus social model of disability
- barriers to participation in development
- social exclusion
- mainstreaming
- Disabled People's Organisations
- participation and choice

Training activities

98 per cent of disabled children in developing countries don't attend school



Introductions



TIME

20 Minutes

HOW TO BEGIN THE PROGRAMME

At the start of the day, introduce yourself and explain how the course will be run. Mention:

- why disability is a development issue – use the handouts section to provide some important global statistics and try to find some facts about the situation for disabled people locally;
- it's designed to be run as an inclusive workshop – there will be plenty of time for breaks and reflection;
- if using interpreters – sign language or spoken – explain how they'll be used to ensure good communication.

Next provide a brief overview of the course structure. Stress this is about raising issues – there are no right answers – and about exploring potential new ways of working. This is to improve the development process as a whole. It's not just about focusing on disabled people. It's also about starting a process of change – it's not the end result.

Inform participants they don't need to write detailed notes as copies of all activities and handouts will be given to them. They should feel free to relax and enjoy the day.



Guessing game



TIME

10 Minutes



MATERIALS

- Participants to have pen and paper (or a good memory!)

Assumptions can be stubborn roadblocks on our journey towards inclusion. This initial activity challenges those, and helps set the framework for the rest of the day's discussions.

Without exception, this session has proved to be an effective icebreaker – something tangible that people remember long after the training has happened. It gives a quick insight into a core issue and helps to quickly settle down participants into the topic and what the rest of the day might bring.

METHOD

- 1 **Ask participants to get into pairs, preferably with someone they don't know well.** Without talking, pairs have up to five minutes to look at their partner and guess at least three things about them. Examples are listed below. Others could be used, depending on the training context:
 - favourite food;
 - favourite colour;
 - favourite hobby;
 - favourite book/film/story;
 - best place/country ever visited;
 - one unfulfilled ambition.
- 2 **Pairs share their answers with each other first and check how accurate they were** (probably not very accurate!).
- 3 **Gather back as a group.** If you have time, people can share answers in the bigger group – especially the unusual and entertaining ones.
- 4 **Ask for general feedback.** How accurate were they? What makes it hard/easy to guess? How did people feel when their partner revealed their answers? Why?

Generally, people will make guesses based on clues such as gender, age, physical appearance and nationality/ethnic group.



Once you feel you've covered all the ideas, start to talk about disability. The problem disabled people face is that non-disabled people will often make assumptions about what they can and can't do – before they even start to get to know them.

Perhaps a non-disabled person encounters a wheelchair user and decides they can't be invited to a meeting because they don't know how they'd get to it. Or they may assume because someone is deaf, they won't be able to understand the discussions.

Both assumptions are likely to turn out to be false. But without taking time to engage with disabled people, it will be difficult to know. There's a danger you'll continue to exclude them because of what you think they cannot do.

MOTIVE

This activity should lead into discussions on the assumptions people make without knowing each other. It's based on non-verbal communication. This is our way of coping with life in a complex social environment. It can be very useful. However, it can also be a huge barrier when assumptions prevent others from succeeding.

Many non-disabled people in the world have negative assumptions about disabled people. These are based on appearance – or on a surface understanding of their situation. No real progress will be made if these assumptions aren't raised and challenged.

This activity can help open up discussions for later activities. It's important for people to start this discussion and consider how they regard disabled people.

Defining disability



TIME

60 Minutes



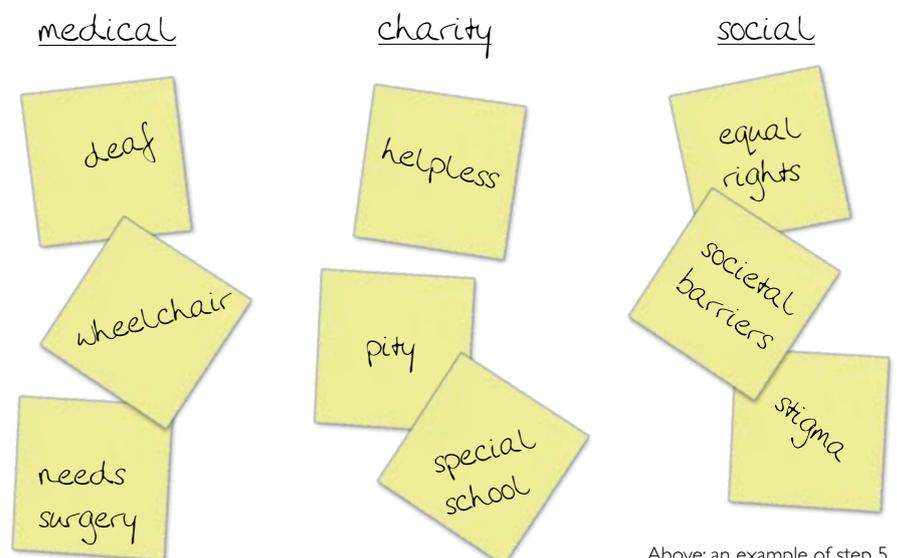
MATERIALS

- **Handout 1** on the models of disability – medical, charity (individual) and social;
- prepared diagrams of the models. These should be displayed when you talk the group through their differences in step 4 of this activity;
- A5 sized cards or large post-it notes and marker pens for each group.

Development programmes often ignore disabled people – or treat them as a special case. This activity deals with different models of understanding of disability, and is central to the training. As facilitator you need to be comfortable with the differences in approaches before you lead the training, because participants will probably want to challenge many aspects before accepting them.

Essentially, both the medical and charity approaches (known as the ‘individual’ models as they focus on the disabled person as the ‘problem’) have targeted disabled people as a separate group – needing specialist or dedicated services, chosen on their behalf by ‘experts’. This is characterised by development initiatives such as provision of prosthetic limbs, rehabilitation or speech therapy programmes; setting up specialist income-generating projects or vocational training centres.

By contrast, the social model makes the assumption that disabled people should participate in all development activities. But it also assumes those actions may need to be adapted for accessibility. It means taking responsibility for understanding how to include disabled people as stakeholders in all mainstream work – and looking for ways to support their participation in community life.



Above: an example of step 5

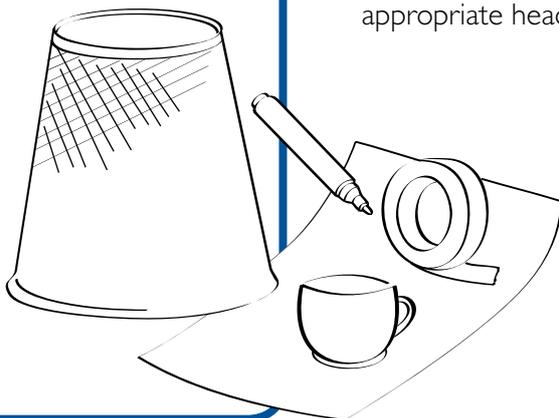


PRACTICAL TIP

The diagrams are useful in helping to explain the different approaches, and are best prepared in advance of the workshop. It's easy to do, even if you're not an artist.

You need two different sized round objects to draw round and something with a straight edge (or a steady hand). We've used a whole variety of different things from dinner and tea plates to upturned wastebaskets and cups!

Stick masking tape around the edge of crockery before drawing to protect it from getting covered in marker pen!



METHOD

- 1 Ask participants** – 'What words do you associate with disability? What words or images come to your mind when you say or think the word "disabled"?' Give them two or three minutes to consider everything that comes to mind.
- 2 Divide participants into small groups of between four and six.** Ask them to talk about the words they've come up with.
- 3 Ask them to write the words they'd like to share with the whole group onto the cards provided** (one word or picture on each card and only on one side). Each group needs to keep their cards safe, ready to share with the others later.
- 4 Bring the whole group back together.** Using the diagrams, explain the concepts of medical, charity (individual) and social models of disability. Use the information in handout 1 to describe each model. Explain to participants they will be given handouts afterwards so they don't need to take notes.
- 5 Having carefully explained each of the different approaches, ask each small group to lay out their collective words on the floor** in front of the wider group under the heading of medical, charity or social. Discussions will follow as participants try to explain why they placed words under particular headings. Encourage people to question whether they think the words are under the most appropriate headings.



This last discussion is important and will often lead to long debates about differences in approach. In reality, it's difficult to separate out words in this way. There are some words or phrases that don't seem to fit anywhere.

That often happens because the original idea behind the statement has mixed motivations. Phrases like 'needs more time' could be viewed as an individual approach because the focus is on the disabled person. But it could be indicative of a social model approach if it relates to the planning of a workshop where you're thinking about ensuring there's plenty of time for everyone to contribute. The debate is important. Encourage participants to think about meanings behind the words. But don't get too drawn into arguments around specific words if the discussion is not especially productive.

MOTIVE

This activity is central to the whole training. Of bigger importance, it is central to what will happen as a result of the training. It is very important participants understand the differences between the individual and social models of disability, as it affects how they will view disability inclusion in programming work. In the past, nearly all international NGO programming work has been based on the individual models of disability. The way forward is to implement social model principle work – that is, disability mainstreaming work. The principles of the social model are those of the UN Convention on the Rights of Persons with Disabilities – it obligates all mainstream organisations to include disabled people in their work.

It is strongly recommended you take time to ensure at the end of the activity participants understand the differences between individual and social models of disability.



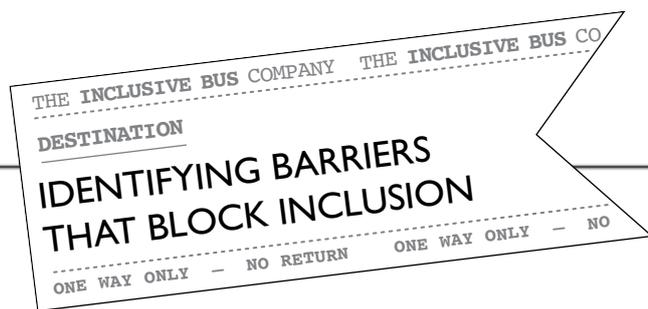
CRITICAL POINTS FOR TRAINERS

Try not to make the mistake of saying medical and charity approaches are 'bad' and social is 'good'. Not only is this too simplistic, but it may also provoke strong reactions from people who've followed the individual approach to disability throughout their career. It's especially difficult for medical and welfare personnel.

Disabled people do often require medical assistance and specialist support. The main issue is choice – often decisions are made on behalf of disabled people, rather than at their request or in consultation with them.



The wall



TIME

60 Minutes

Steps 1 to 4: 50 mins
Step 5: 10 mins



MATERIALS

- Prepare three flip charts (see p.23) on different categories of barriers/discrimination (environment, policy/institutional, attitude);
- **Handout 2** on barriers;
- A5 cards, or large post-it notes, and marker pens for each group.

Barriers can feel almost like brick walls. But once identified they can be challenged and broken down allowing more and more disabled people to be included in development.

Barriers are broken down into three main areas – attitudinal, environmental and institutional (or policy). This makes the issues more manageable and highlights areas where direct intervention can make a difference.

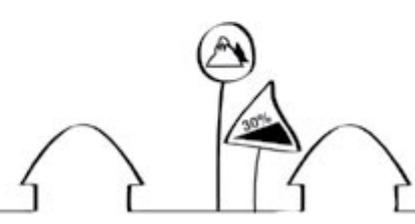
Ensure you're familiar with the different types of barriers before leading this session.

Environmental barriers are often easiest to identify. But don't let the group get too focused only on physical access – steps, narrow pathways, uneven surfaces for example. Access issues are just as significant for those with sensory or communication impairments where information isn't available in formats they can understand.

Institutional barriers are some of the most difficult to identify. Without a proactive search for them, they won't be as immediately evident. That's because they're often linked to social and cultural norms and written into policies and legislation. The way to start identifying them is to focus on sectors in which you work, and try to map the legal, cultural and social practices that might need addressing. Consulting with local disabled people will be an essential part of helping identify them.

Attitudinal barriers are the most important to identify – time and time again they are the main reason prohibiting progress on disability inclusion. Negative attitudes and assumptions have led to many disabled people believing themselves to be worthless, dependent and in need of support. This cycle of charity and dependency can be difficult to break.

You need to draw out all these issues – and more – as you talk through barriers with the group. It's worth trying to identify some local examples in advance.



PRACTICAL TIPS

A good way of using this tool is with groups of disabled people – or even better with community groups that include disabled people. Prepare the wall statements with some of your ideas about barriers, then compare them to the ones local disabled people have identified. This can bring up issues that are missed when disabled people aren't included in consultations.

In the training room display the barriers in the order shown on the next page. This is different to the order in handout 2, as attitude is the biggest barrier. Most people tend to think of environmental barriers and it will probably be the fullest flip chart, many are often surprised that attitude is the biggest barrier!

METHOD

- 1 **Ask everyone to take a few moments to think about their daily life – work, social, home etc.** Imagine what obstacles might exist if they were disabled. For groups of disabled people ask them to describe what obstacles they face on a daily basis. Think as widely as possible – don't just focus on physical things. Write a list.
- 2 **Divide into mixed groups of four to six.** Give each group post-it notes (or A5 pieces of paper, with tape to attach to flip charts). Ask the groups to combine their observations and write down one idea per post-it note or piece of paper.
- 3 **After 15 minutes, bring the whole group together and display the prepared flip chart sheets to form a wall.** Explain the 'bricks' represent barriers to inclusion faced by disabled people and are grouped into three main forms – environment, policy/institutional, attitude. Explain the three barriers to the group. Distribute the handout now or at the end of the exercise.
- 4 **Ask one person from each group, in turn, to place their post-it notes/pieces of paper onto the 'wall' – thinking about the best heading (attitude, environment, institutional) for each post-it/piece of paper.** Discussions should flow as people try to decide where to place their obstacles and why. If people aren't talking, and you can see ideas going into barriers that are not appropriate, lead a discussion on it. Use this to help people understand the reasons behind the barriers and categories.
- 5 **Invite people to discuss their experiences of identifying barriers and what they've learned.** Use the lessons learned to make key points (based on the 'motive' section).

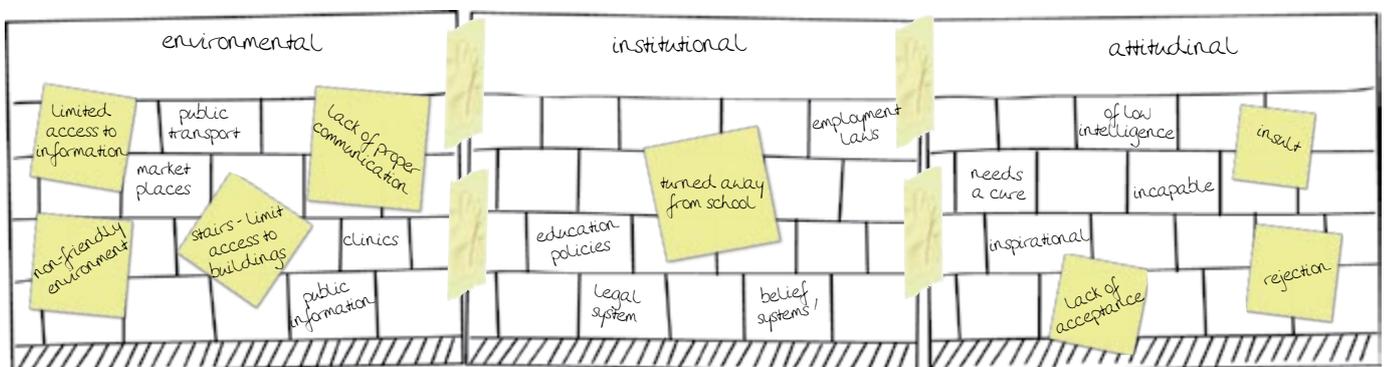


MOTIVE

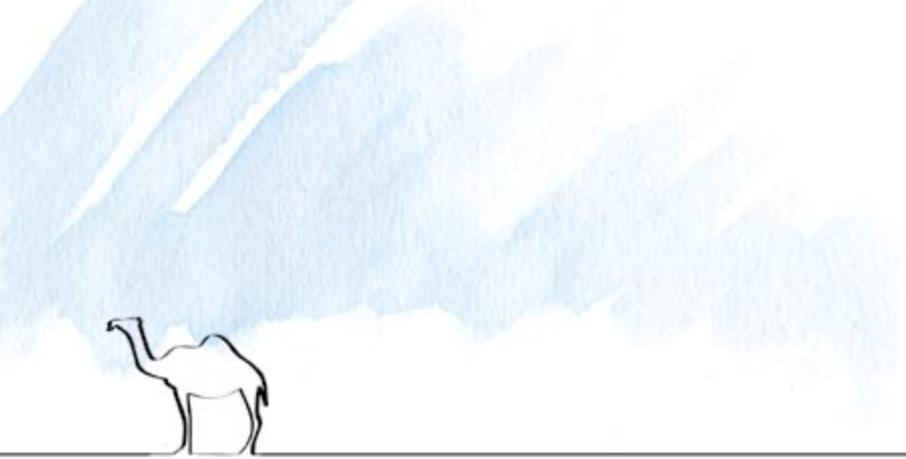
This is a good exercise for groups who haven't thought about different forms of barriers that exist for disabled people – in other words, discrimination. The activity flows well from the session on models. It will help explain the barriers introduced in the description of the social model in Activity 2.

This activity is done in a systematic way, breaking the barriers down into three main forms – environmental, institutional (or policy) and attitudinal. This makes the issues more manageable and highlights areas where direct intervention can make a difference. The largest barrier is often the attitudinal one, and that should be stressed as the session progresses – or in the summary at the end.

Attitude barriers can be reduced through awareness-raising events, campaigns or training. Once identified, institutional barriers can form the basis of an advocacy strategy. Environmental barriers can be dealt with as you design project activities and inputs, making provisions for appropriate access needs.



↑
this is how your "wall" should look when you are finished



Game of life



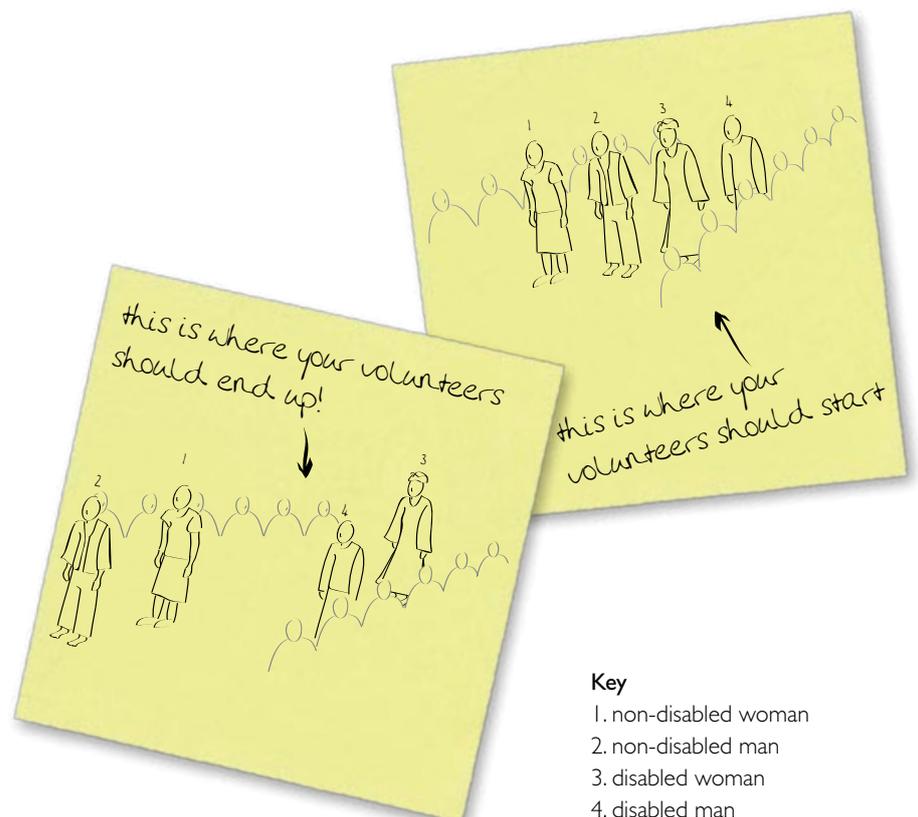
TIME

60 Minutes

Story is a powerful means of conveying your message. And it's used to great effect in this visual representation of discrimination. It helps to reinforce concepts raised.

When the story begins and participants start to think about whether a disabled infant would be as welcome as a non-disabled one, you can talk about some of the prejudices surrounding disability – and some of the causes of this stigma. Throughout the story there are many opportunities for raising issues of concern. So it's helpful if you prepare well by researching local attitudes, beliefs and challenges.

This is the activity where the main point of the training course 'hits home'. People have been transformed by this activity. Having a tea break afterwards is good, as participants often wish to discuss and reflect on the issues raised here with each other, and need a little time for the message to absorb. This can make the final part of the afternoon especially productive.



Key

- 1. non-disabled woman
- 2. non-disabled man
- 3. disabled woman
- 4. disabled man



CRITICAL POINT FOR TRAINER

It's important that people volunteer for their roles.

In some situations, religious or traditional beliefs may preclude some from participating. Be aware and respect that. In some cultures, even to imagine being disabled can be seen as 'tempting fate'.

METHOD

Setting up the room is important. You may need to spend time reorganising the chairs. You'll need enough space for four people to stand side-by-side, with the other participants seated around the edges of the room, facing towards the volunteers. Creating a 'corridor' in the middle of the room, enabling you to use the full length of the room for the exercise, is ideal.

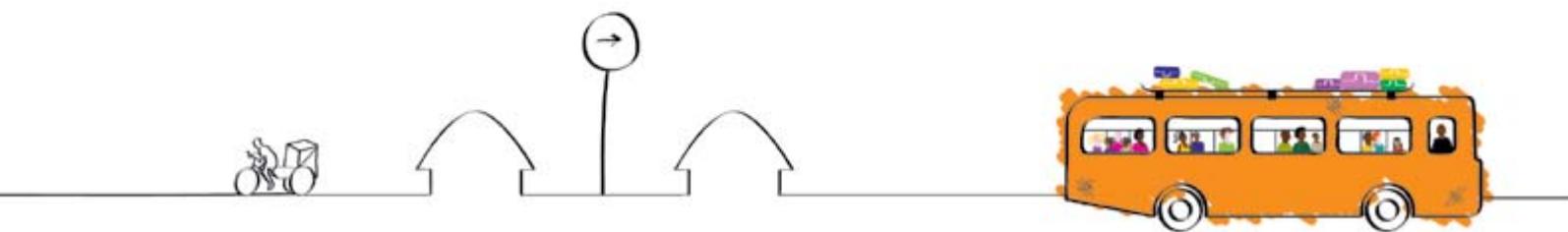
1. **Ask for four volunteers from among the group** (ideally, two men and two women), willing to stand for about 30 minutes to represent the following groups:
 - non-disabled men;
 - disabled men;
 - non-disabled women;
 - disabled women.

Stress this is NOT a role-play exercise – the volunteers will be representing a group of people from within a village. Many people do not like role-play, hence the need for reassurance!

2. **Assign each volunteer a role.** Explain how you'll be telling a life story, taking the characters on a journey from birth to old age. As you reach each significant life event, you'll ask them to respond as they think their character (or their family) would react. They'll need to take:
 - two steps forward for a very positive or very successful experience;
 - one step forward for a positive or successful experience;
 - one step back for a not-so-positive or not-so-successful experience;
 - two steps back for a negative or unsuccessful experience.

Once your volunteers understand what they'll be required to do, reinforce they are representing a group of people, so they should respond accordingly. Encourage them to avoid thinking about specific impairments or basing decisions on their own life experiences. Also, their response should be based on what they think is currently accurate for their culture and situation – not what it ought to be.

After each life stage and volunteers' responses, allow time for the others to react and comment. If there's disagreement, the group should decide by consensus and the volunteer may be asked to alter their move. The facilitator's role is to assess when to intervene and



comment to clarify reasons for decisions and to bring out and discuss any prejudicial points. The specific impairment is not relevant to the main point of this exercise, so try not to focus on this too much. It won't alter the essence of the activity.

- 3. Set the scene for the story.** Since you want to emphasise links between disability and poverty, consider placing the story in a typical village. Describe it in as much detail as you can, explaining that income poverty levels are generally quite high – although most families have land and access to safe water. For entrepreneurs, opportunities exist in the nearby town where there are also health and educational facilities.
- 4. Start with the first life event, as if telling a story...**ask for comments and suggestions from the rest of the group.

'One fine day, after a long wait of nine months, your character is born. How does your family feel when they see who you are? Make your moves.'

Note what might happen:

- family is very happy (non-disabled son born), *two steps forward*;
- quite happy (disabled son/non-disabled daughter), *one step forward*;
- not happy (disabled son), *one step back*;
- very unhappy (disabled daughter), *two steps back*.

'Now you are a bit older, and it's time to start thinking about school. How likely is it that you will be able to attend school? Make your moves.'

'Now you are 20. You'd like to get married, or form a relationship. How much do you think this will be possible for you? Make your moves.'

'You like to keep busy and want to make some money for your family. You try to get a job. How easy will it be for you to find one?'

'A few years go by. Everyone in your age group is having babies. How much will this be a possibility for you?'

Check if the disabled woman takes two steps back, or is instructed to do so by the group. Why did this happen? They may say it's because most disabled women are physically unable to have children – a common myth.



PRACTICAL TIP

Game of life can be used as a 'stand alone' activity for groups with limited amounts of time. There's no need to prepare any materials, and it can be run in as little as 30 minutes (ideally, one hour). It has a strong impact on people and always provokes many discussions. So it's ideal if you have limited time to get your message across.



CRITICAL POINT FOR TRAINER

In groups with disabled and non-disabled participants, this activity can have additional sensitivities. So it's really important participants feel comfortable enough with each other to honestly explore the situation from their perspectives. Be aware of this if you are a non-disabled person and it's the first time you've worked with disabled people.

Two steps back may well be an accurate response for a different reason – disabled women often don't have children because society thinks they can't or shouldn't.

'Now you're in your 40s. You have a lot of experience of life. You want to help your community by becoming involved in local politics. How likely are you to achieve this goal?'

5. Ask the group:

- Who is in the best position now? Who is in the worst place?
- Volunteers, how does this make you feel?
- Does any of this surprise anyone?
- Is it helpful as a tool for reminding us that disability and social exclusion seriously affects people's abilities to avoid poverty?
- The non-disabled man at the front of the exercise is regarded as living in poverty – what does this imply for disabled people?

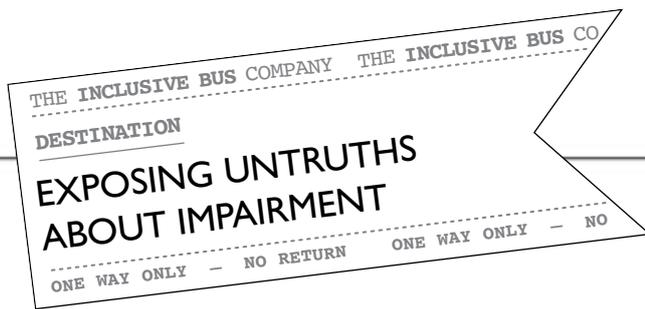
The most powerful way to end this session is to ask the group to look once again at where the characters are standing. Recall that this was all taking place in a rural location where general levels of poverty are quite high. Even though the non-disabled characters are well ahead of the disabled ones, they're by no means wealthy. Ask the group – who benefits from your development programmes at the moment?

MOTIVE

Including disabled people is an important issue for poverty reduction – that's the message of this session. It should help show why they are especially vulnerable to chronic poverty. It also provides you as facilitator with a good opportunity to talk about many different development issues that affect disabled people – but which rarely get discussed.

To many, this session will dramatically reveal things about their communities which they may never have considered before. It can be fun. Humour can take the edge off the hard facts exposed by the game. But some participants can find it distressing, because it makes plain some painful, personal truths.

Unmasking myths



TIME

30 Minutes



MATERIALS

- **Handout 3**
on different types
of impairment.

Myths have emerged across all cultures about why people are born with or acquire impairments. This activity is designed to help participants appreciate some of those. Project staff going into villages, holding discussions, and including disabled people in meetings should have an awareness of local superstitions.

There are many examples of myths – ranging from ‘bad’ spirits, punishment for sins, to fear of seeing a disabled person while pregnant. Where factual knowledge on the causes of impairments is limited, these beliefs can be powerful and pervasive. They will profoundly affect the way disabled people are treated and view themselves.

Programme staff need to be aware of this. It will have an impact on how well disabled people are accepted into project activities by the community. A session like this, held in the community, could be a useful starting point for introducing disability inclusive activities.

Seeing a disabled person
whilst pregnant means
that the infant will be
born with a disability

fact or myth

Road accidents are
a common cause of
disability

fact or myth



TELLA STORY...

In Kenya, the Samburu people believe having a child with albinism is extremely unlucky. They don't understand how two black people can produce a white child. So the father is allowed to question the paternity. He does this by leaving the infant across the gate of the cattle boma (compound) as the cattle are released. If the child isn't trampled by the cattle and survives, it's assumed the child is his.

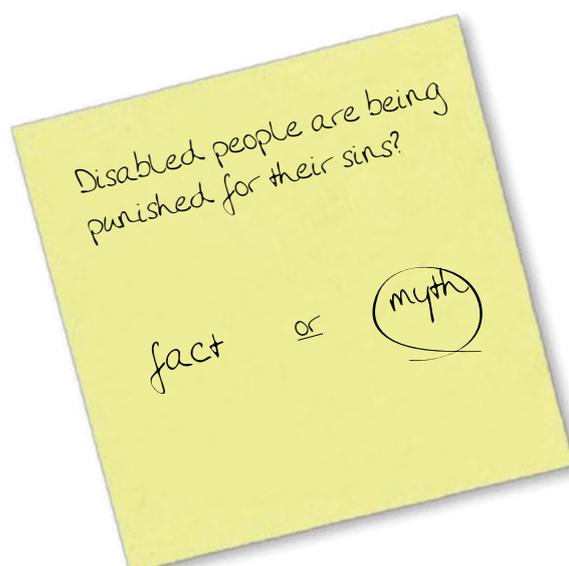
There are other hazards the albino child has to endure. Mothers believe if they leave the child in the sun, the burns the child receives will settle and cause the skin to darken. This causes much suffering to the child and is likely to shorten life expectancy. There are very few albinos in Maasai culture.

METHOD

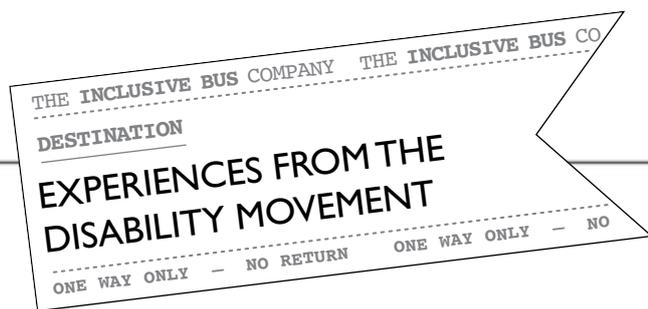
- 1 **Talk through some of the most common forms of impairments and their typical causes.** It's useful to help participants understand the language associated with different disabilities. Distribute the handout on different impairment groups.
- 2 **Ask participants to describe some common reasons given locally for the causes of impairments – and some common reactions to disabled people.** List the most popular myths about disability onto flip chart paper which can then be displayed.
- 3 **Tell the group the true-life story from 'TELLA STORY...' in this section.** Are there local cultural beliefs like the one from Kenya? Lead a discussion. Help the group understand how local people perceive disability. Some myths of impairments are contributing to negative – sometimes hostile – attitudes towards disabled people.

MOTIVE

The session should focus on **process** rather than outcome. It allows participants to voice the superstitions. The facilitator can help clarify the more likely causes of impairment. The outcome is that people have a chance to talk about superstitions, so participants can understand these are myths, not facts.



Reality check



TIME

60 Minutes



MATERIALS

- **Handout 6** on disability organisations and Disabled People's Organisations (DPOs).

Local context is where reality 'bites' where development and disability are concerned. Either of the following two activities can be used at this stage, depending on that context. Where you have connections with and knowledge of the local disability movement (DPOs and self-help groups), invite them to give a presentation as outlined in this session. If you are not involving DPOs and self-help groups, do the alternative Activity 7 (Excuses excuses) at this point.

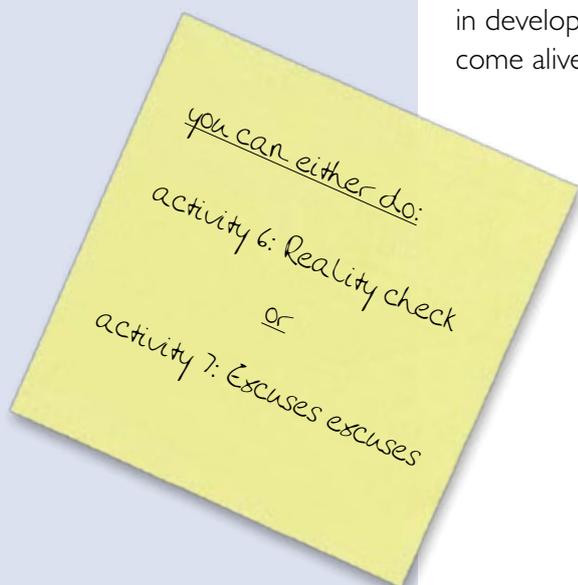
METHOD

Where you have a good relationship or knowledge of the local disability movement, this can be an excellent opportunity for participants to learn first-hand how disabled people are working to influence communities, service providers and government for inclusion.

Invite one or two local DPO representatives to give a short presentation on the work of their DPO. Then answer questions from the group.

MOTIVE

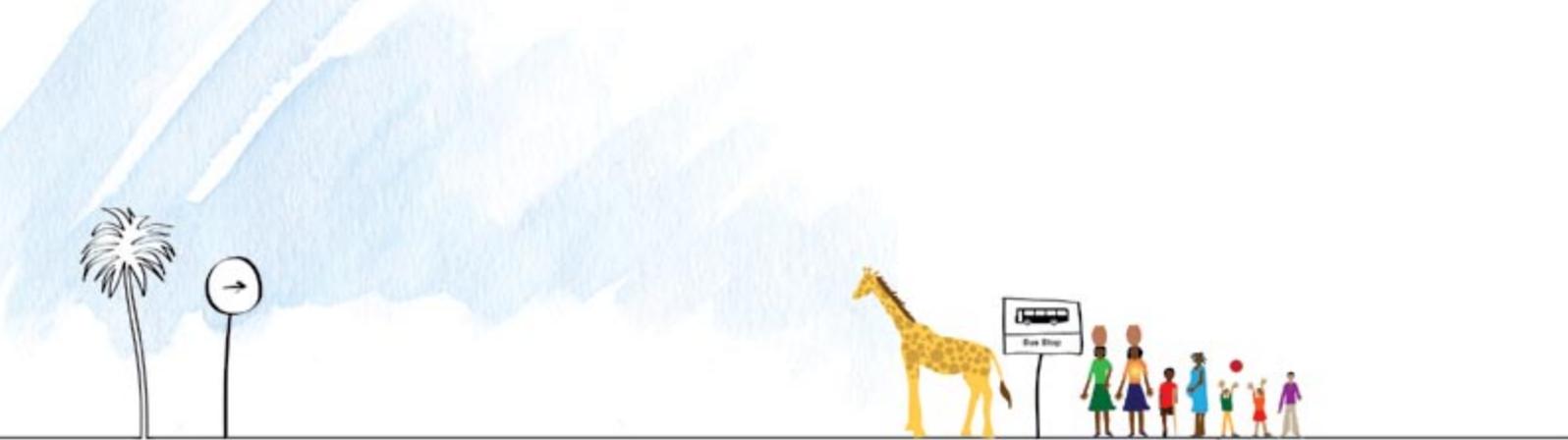
Feedback shows that direct input from DPOs – especially where they share stories from their own experiences – is powerful in the training room. This session is about highlighting why disabled people are important in development work. So first-hand accounts make the local situation come alive.



CRITICAL POINTS FOR TRAINER

Brief presenters ahead of the workshop. Here are some guidelines:

- describe your DPO – when it was set up, who it represents and where it works;
- describe some of the main achievements of your DPO over the last year;
- what are some of the main barriers facing disabled people locally?



Excuses excuses



TIME

60 Minutes



MATERIALS

- **Handout 4** on disability (or make a display of disability statistics);
- **Handout 5** on common myths around disability inclusion;
- **Handout 6** about disability organisations and DPOs;
- prepared questions (given in step 1) written on flip chart paper;
- flip chart paper and marker pens for each group.

Why are disabled people excluded from most mainstream programmes? That's the core question. And it's tackled head-on in this session.

Even though agencies may focus on different areas – from child-centred development to micro-finance – many of the reasons given for not considering disabled people's needs are remarkably similar. These statements are issued by organisations that could easily be including disabled people.

Encourage the group to confront these issues in as non-threatening a way as possible. Try to keep discussions as fun as you can to avoid people becoming defensive. You're not judging the work that's happened. But you do want to help the group understand why disabled people have been excluded for so long.

METHOD

1 Ask the whole group the following questions:

- do you actively include disabled people (or measure their participation) in your development programmes?
- If not, why don't you actively include disabled people in your development programmes?

The key part of these questions is the word '**actively**'. This should be stressed when you pose the questions. Encourage people to be honest about their answers – this will give them the best opportunity to analyse the issue.

2 Assuming the group does not actively include disabled people, list down all the reasons people give onto flip chart paper. Possible answers will include – it's expensive; time-consuming; we don't have the experience; we don't know how to; why should we, this is one more marginal group amid many others; it's not practical in our type of work; etc.

3 Explain the most likely common misconceptions – and their responses – given overleaf (see **Handout 5 – Common myths about inclusion** for further analysis):



CRITICAL POINT FOR TRAINER

A good way to start this session is to talk through some of the more serious statistics relating to disabled people in developing countries. Many development agencies aren't aware there are so many disabled people and that they make up such a significant proportion of the world's poorest people.

'We need to sort out the problems of "normal" people first.'

'It's not cost effective.'

'There aren't many disabled people here, so it's not an issue.'

'We don't "do" disability.'

'We don't have the skills.'

'Let's create a special programme.'

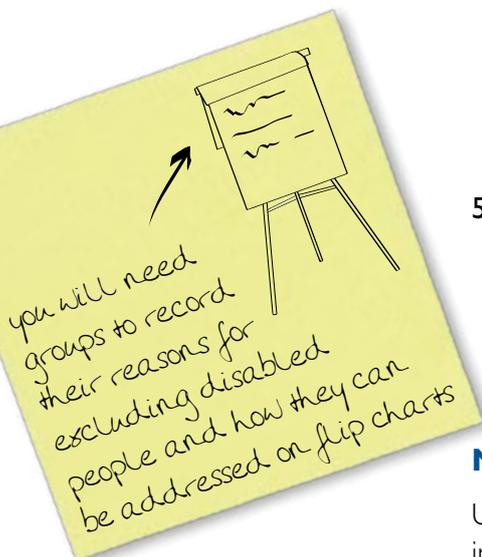
4 Divide participants into groups of four to six. Give each group a selection of the excuses they've come up with. Ask them either to turn them into positive statements about how the organisation is working with disabled people – or develop a reply refuting the statement. They need to imagine they're facing people who are coming up with all these reasons why they're not going to include disabled people. Their job is to reassure them that inclusion is good development practice – and this will improve the effectiveness of the programme as a whole.

5 Ask the groups to present a selection of their favourite responses to the rest of the participants. They can do this in whatever format they choose. Some groups might like to illustrate their ideas with pictures, perform a short dialogue highlighting the debate or simply describe their ideas.

MOTIVE

Uncovering barriers as to why disabled people are not routinely included is the first most important step to getting over their exclusion. They're not included because there are mechanisms preventing that. Identifying what those mechanisms are is central to developing a more inclusive programme.

By asking people to defend excuses in a light-hearted way, you'll be providing them with insights into their own perceptions – and helping prepare them for how others might react to their plans for disability inclusion.



Feedback forum



TIME

15 Minutes

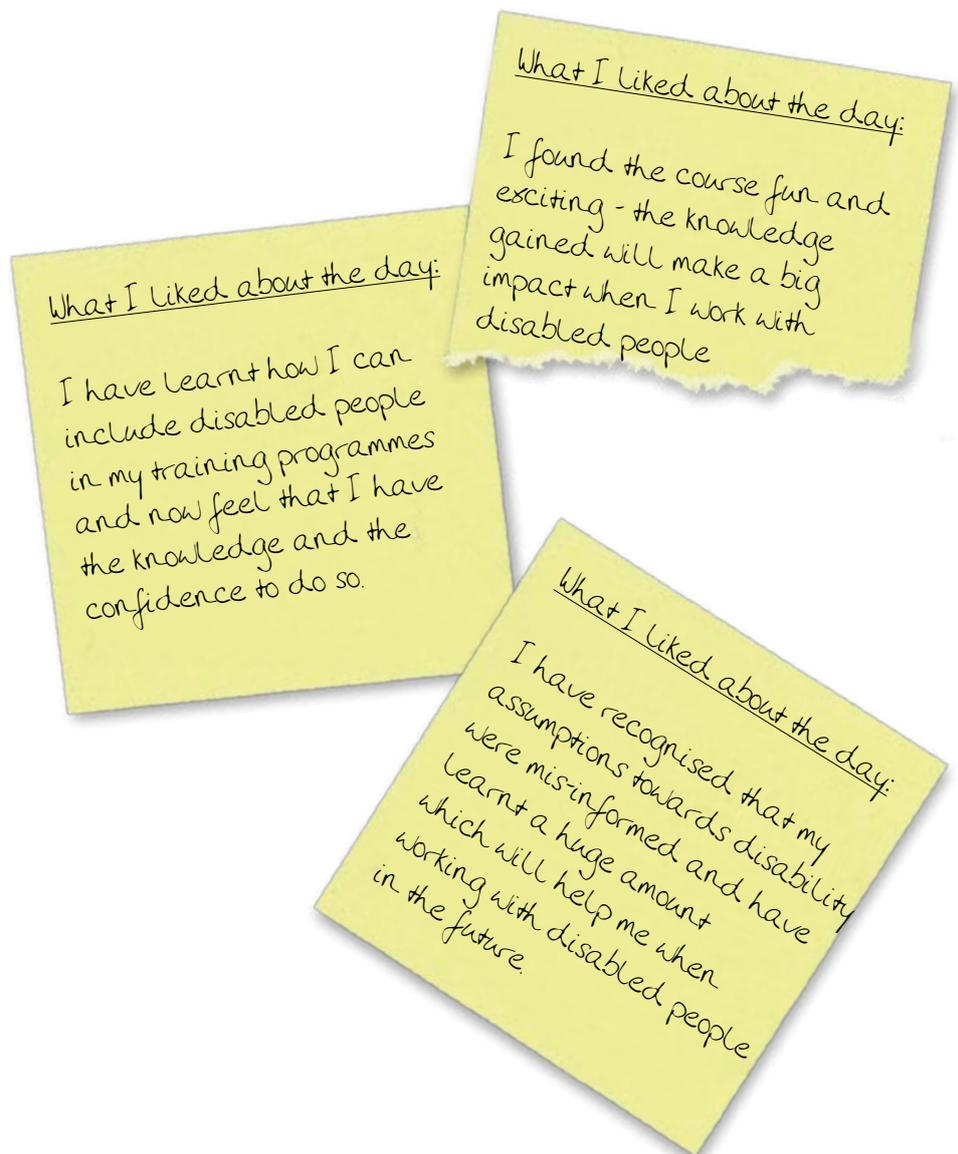


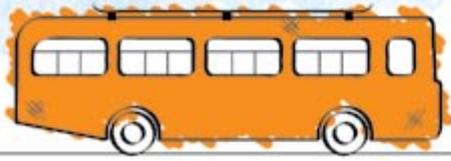
MATERIALS

There are many ways to carry out workshop evaluations. We recommend keeping things as simple as possible. Prepare two sets of blank flip charts headed with the questions:

- what I liked about the day;
- what I think could be improved.

Have you made a difference? You need to find out. Allow time at the end of the day to summarise and restate the main concepts covered – e.g. models, barriers, and importance of attitudes. Give people the chance to ask any remaining questions.





METHOD

- 1 **Ask each participant to think about the sessions that made the biggest impact on the way they think about disability and development.** You can talk about these with the group if they are willing to share their thoughts.
- 2 **Allow them about 5 minutes to individually note three action points on what they plan to do differently in their work from now on.** Encourage them to think about each of the three main barriers and try to find one action point for each barrier.
- 3 **Give each participant access to post-it notes or A5 blank pieces of paper.**
- 4 **Ask them to write up any reactions they have to the workshop using the two questions outlined in ‘materials’ and stick them to the blank flip charts before leaving.** This is an informal way of gathering information that often provides some good feedback.

Finally, before participants leave, ensure they have the full set of activity descriptions and training handouts. You may wish to give them in soft copy form (such as on a CD or memory stick) as well as hard copy form. This will enable them to take the training back to their own work areas – and consider running their own courses!

Handouts

more than 80 per cent of disabled people live below the poverty line in developing countries



Handout I

MODELS OF DISABILITY

HOW TO USE THIS HANDOUT

Use this handout with the following activity:

- **Defining disability**

INTRODUCTION

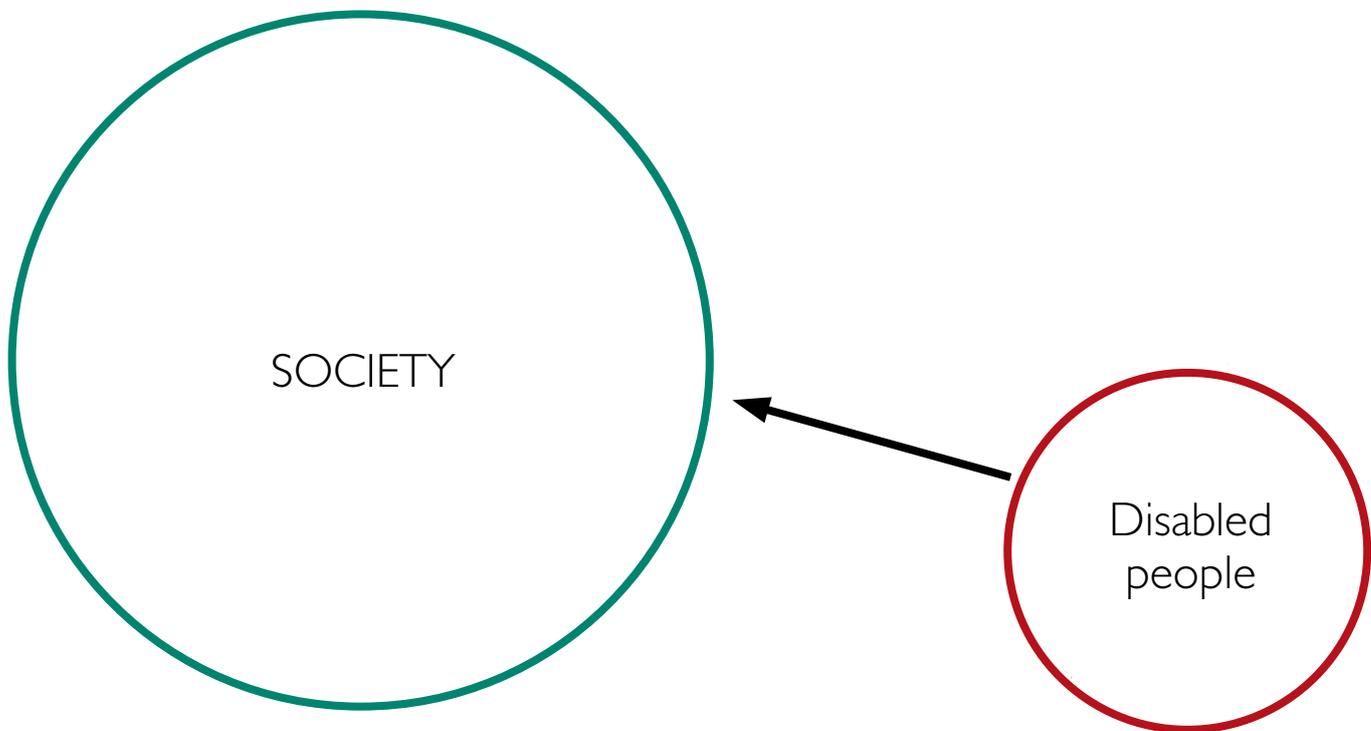
Everyone has a right to such things as health, education and income generation. But the needs of disabled people have traditionally been treated as separate and specialised which has put them outside mainstream society. The UN Convention on the Rights of Persons with Disabilities challenges this narrow approach. The emphasis for inclusion is placed on society rather than on disabled people. They should be seen as whole people with the same needs as others, able to choose how they are supported.

There are three ways disability has been approached in development. The first two models – medical and charity approaches – focus on barriers to participation being with the disabled individual. The third way – the social model – focuses on barriers being with society's view of disabled people.

Handout 1

INDIVIDUAL MODELS:

MEDICAL APPROACH

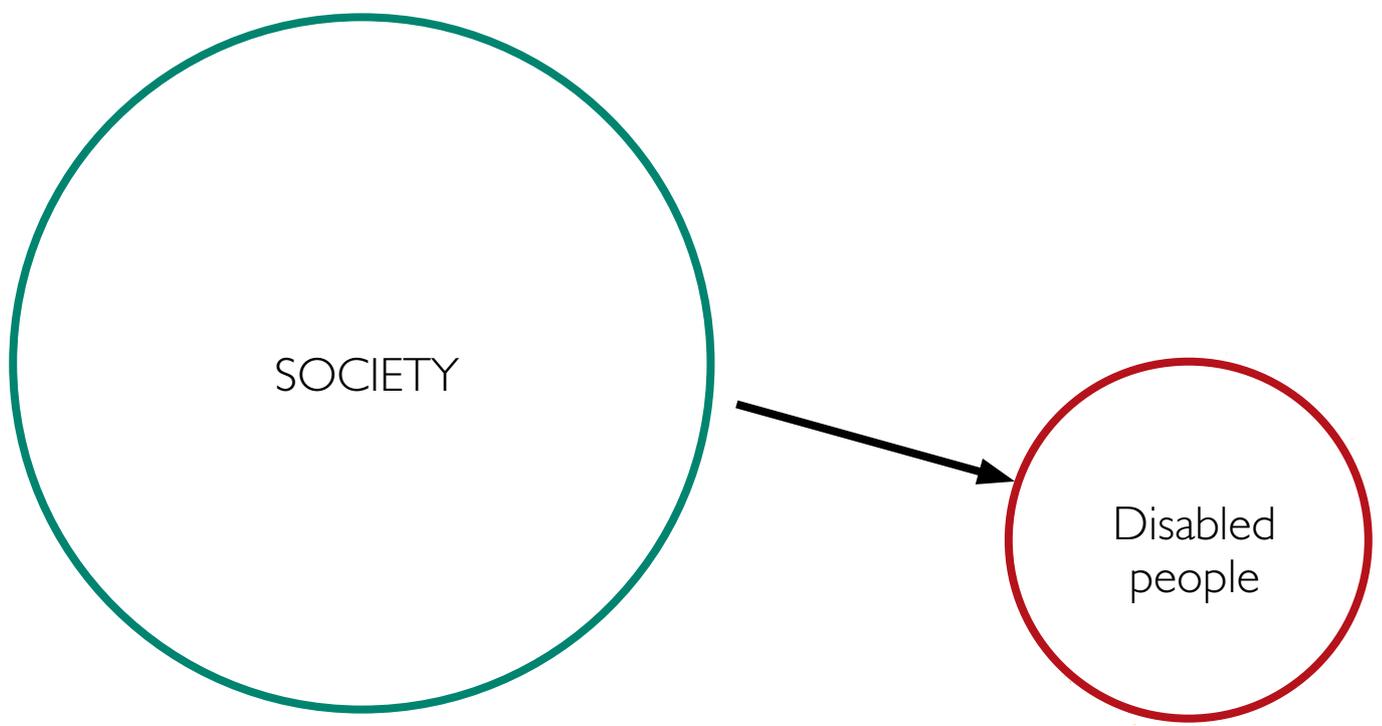


Activities 'fix' disabled person, who is 'sick', so they can join 'normal' society

- **disability is a problem in the person**
- a traditional understanding of disability
- focuses on a person's impairment as the obstacle
- seeks to 'cure' or 'improve' individuals to 'fit' them into society
- defines the disabled person only as a patient with medical needs
- segregates disabled people from the mainstream
- offers only medical help, carried out by specialists
- expensive, tends to benefit relatively few

Handout 1

INDIVIDUAL MODELS: **CHARITY APPROACH**

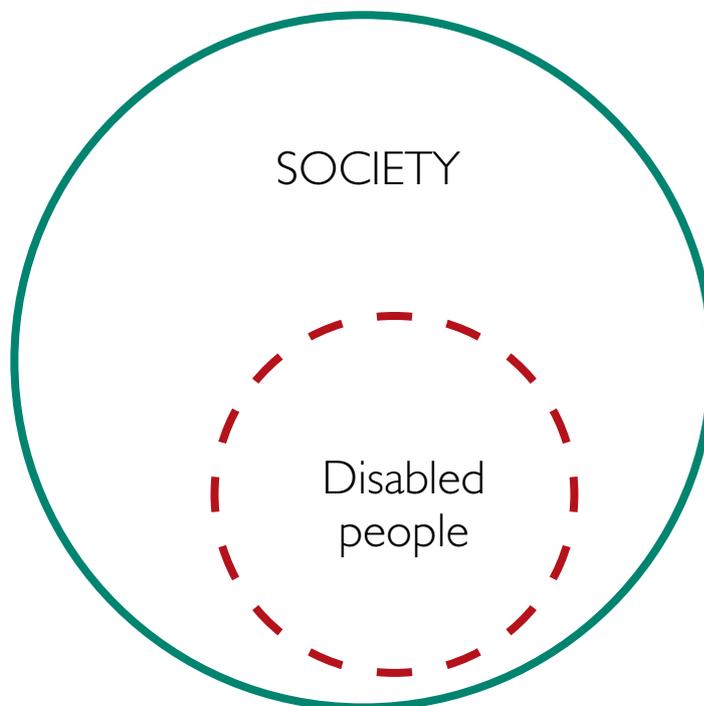


Activities 'help' disabled person who is 'helpless' and outside 'normal' society

- **disability is a problem in the person**
- they are seen as 'unfortunate', 'dependent' or 'helpless'
- they are regarded as people who need pity and charity
- assumes people with impairments cannot contribute to society or support themselves
- provides them largely with money or gifts, such as food or clothing
- disabled people become long-term recipients of welfare and support
- aid provided by specialist organisations not mainstream development
- disabled people viewed and kept as separate group

Handout 1

SOCIAL MODEL: **INCLUSIVE APPROACH**



Activities focus on inclusion – disabled people are part of society

- **focuses on society, not disabled people, as the problem**
- regards disabled people as part of society, rather than separate
- people are disabled by society denying their rights and opportunities
- sees disability as the social consequences of impairment
- disabled people's needs and rights are the same as non-disabled people's – e.g. love, education, employment
- activities focus on identifying and removing attitudinal, environmental and institutional barriers that block inclusion

Handout 2

BARRIERS THAT BLOCK PARTICIPATION

HOW TO USE THIS HANDOUT

Use this handout with the following activity:

- **The wall**

INTRODUCTION

There are three big roadblocks preventing disabled people from participating in society on equal terms with non-disabled people. Here they are...

ATTITUDINAL

Prejudice, discrimination and stigma cause the biggest problems for disabled people, who are assumed to be one or more of the following:

- incapable/inadequate
- of low intelligence
- in need of a 'cure'
- needing 'special' services or support
- dependent
- inspirational/marvellous/exceptional

People who make these judgements treat the disabled person as superfluous or superhuman. They either fail to respond to the individual – with all their inherent personality, strengths and weaknesses – or they assume they have 'superhuman' abilities to cope with their impairment.

Non-disabled people can respond with fear, pity, repulsion, or a sense of superiority. These assumptions and emotions are reinforced by the media. Negative language reflects and can reinforce prejudices. Disabled people wish to change the language used by non-disabled people about them – especially language that is offensive and inaccurate.

Handout 2

ENVIRONMENTAL

Disabled people encounter these barriers in areas such as:

- public transport
- hospitals and clinics
- schools and housing
- shops and marketplaces
- offices and factories
- places of worship
- media and communications
- public information systems

Most people think of the physical barriers in this category – e.g. a health clinic is inaccessible for wheelchair users if it has steps and narrow doorways. It's relatively easy to identify these – in consultation with disabled people – once aware.

But communications can also be disabling for those with sensory impairments – e.g. for Deaf people if there's no sign language; for those with visual impairments if medication isn't appropriately labelled. Poor communication can have devastating results where important school-based education campaigns happen (e.g. HIV and AIDS).

Students with hearing, visual or intellectual impairments are unlikely to access vital information unless their access needs have been met. And since 98 per cent of disabled children in developing countries don't attend school, they'll miss out on important education and information. A Ugandan study found 38 per cent of women and 35 per cent of men with impairments had a sexually transmitted disease at any one time.

Handout 2

INSTITUTIONAL

These barriers exclude or segregate disabled people from many areas:

- legal system
- employment laws
- electoral system
- education policies
- health service provisions
- social services
- belief systems and religion
- humanitarian/development agency policies

Many of the systems we take for granted have become 'no-go' areas for disabled people. Their marginalisation is similar to the negative treatment of women and ethnic minorities.

Exclusion from institutions has a knock-on effect – poorly regulated special education often makes fewer academic demands on pupils, and smaller schools expose them to a limited range of cultural experiences. The virtual exclusion of disabled people from teacher training colleges also limits the number of qualified disabled teachers as role models for disabled and non-disabled pupils in mainstream schools.

Families make assumptions their disabled child will never work independently. So they don't press the government to provide suitable formal education, or encourage the child to pursue a career. With such low expectations, disabled people can easily become fatalistic about their own prospects.

Micro-finance institutions often have policies which are highly discriminatory. They may exclude deaf people on the assumption they won't be able to talk directly with staff; or refuse to lend to a visually impaired businessperson on the grounds they're not likely to make a profit as a disabled entrepreneur. These are real examples.

Handout 3

DISABILITY AND DIFFERENT IMPAIRMENTS

HOW TO USE THIS HANDOUT

Use this handout with the following activity:

- **Unmasking myths**

WHAT DO WE MEAN BY DISABILITY?

- the result of limitations imposed on people with impairments
- those limitations prevent their full participation in society
- attitudinal, environmental and institutional barriers prevent their inclusion.

WHAT DO WE MEAN BY IMPAIRMENTS?

- problems in body function or structure
- examples are: lacking part of or all of a limb; or a limb, organ or body mechanism that doesn't fully function
- may be long-term or short-term, physical, sensory, neurological, intellectual, mental or physiological
- multi-impairments are where a person has more than one impairment
- conditions caused by disease or injury that affect a person's functioning or appearance.

WHAT CAUSES THEM?

- some impairments are congenital due to genetic factors
- other impairments can be caused by an injury or illness before birth
- others can be caused by injury or illness after birth
- a person can have multi-impairments from one or more causes.

HOW DO THEY AFFECT PEOPLE?

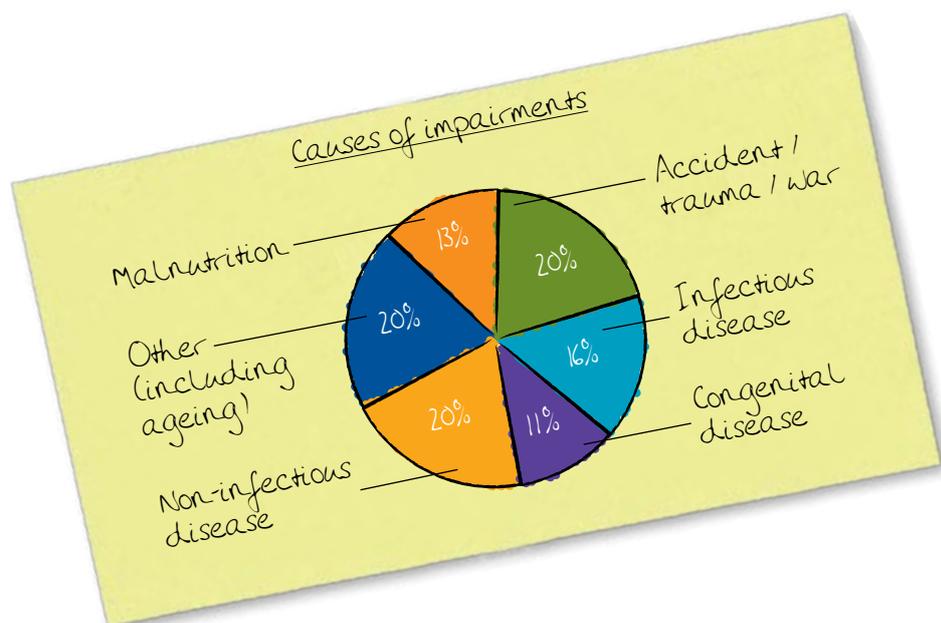
- *physical* impairment affects a person's body movement and/or appearance (e.g. cerebral palsy, limb loss)
- *sensory* impairment affects sight, hearing, speech, smell, taste, sensation/feeling, physical balance (e.g. blindness, hearing loss)
- *neurological* affects nervous system, speech, motor skills, vision, memory, muscles, learning abilities (e.g. epilepsy, multiple sclerosis)

Handout 3

- *intellectual* affects cognitive functioning and behaviour (e.g. Down's syndrome, learning difficulties)
- *mental illness* affects thinking, moods, ability to relate and capacity for coping with life (e.g. schizophrenia, bipolar disorder).

HOW SHOULD WE RESPOND?

- use the social model to understand disability
- challenge stigma and discrimination
- realise that limitations may depend on other factors such as personality, background, support networks, cultural context
- note that regardless of their impairment, a person can be 'disabled' by society because of stigma and prejudice.



Handout 4

THE GLOBAL TRUTH ABOUT DISABILITY

HOW TO USE THIS HANDOUT

Use this handout with the following activity:

- **Excuses excuses**

INTRODUCTION

Not all disabled people have problems with their health or impairment. But most face poverty, discrimination, prejudice and stigma. Many lack access to public services – health, education, clean water, sanitation and housing. Disabled children and adults are more vulnerable to conflict, HIV and AIDS, violence, abuse and neglect.

More than 600 million of the world's population have impairments, with three-quarters of them living in developing countries. In addition, 1 in 4 of the poorest people have an impairment. If you consider the exclusion and discrimination that disabled people and their families face, the impact of these figures will be even greater.

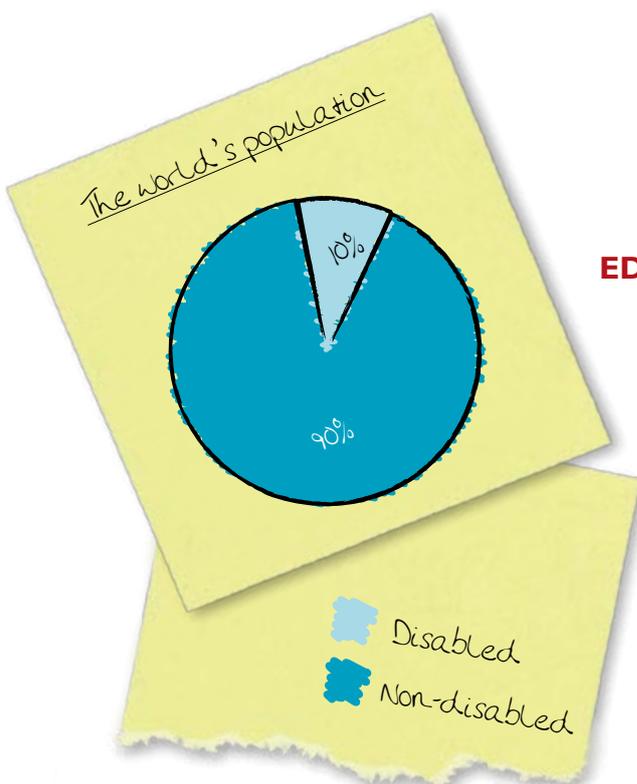
Here is just a selection of facts and figures that paint the real picture for disabled people across the globe.

POVERTY

- there's a direct link between poverty and disabling impairments
- 50 per cent of impairments are preventable and poverty-related
- 20 per cent of impairments are caused by malnutrition
- more than 80 per cent of disabled people live below the poverty line, in developing countries.

EDUCATION

- 98 per cent of disabled children in developing countries don't attend school
- 40 million of the 115 million children who don't attend school have a disability
- disabled female children are less likely to attend school in comparison with disabled male children
- literacy rates for disabled individuals are as low as three per cent globally, impacting important issues such as communication on HIV and AIDS.



Handout 4

Sources

- Australian Council For Overseas Aid
- UK Department For International Development
- United Nations Educational, Scientific and Cultural Organisation
- Child Rights Information Network
- Motivation
- World Health Organisation
- United Nations Children's Fund

HEALTH

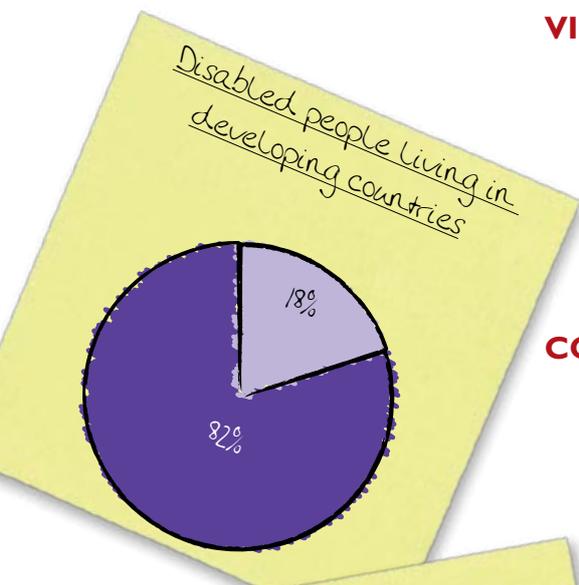
- only two per cent of disabled people in developing countries have access to basic services and rehabilitation
- 80 per cent could have their needs met in the community; only 20 per cent would require specialist attention
- less than 0.1 per cent of deafblind people in developing countries receive appropriate support
- in countries where under-five mortality has decreased to 20 per cent, mortality rates for disabled children may still be 80 per cent
- more than 80 per cent of the 50 million people affected by epilepsy live in developing countries – treatment costs can be as low as \$5 US per year
- 20 million people who need a wheelchair don't have one.

VIOLENCE

- a study in India found 90 per cent of people with intellectual impairments will experience sexual abuse, often in childhood
- disabled children are more likely to experience violence from birth
- disabled children are targeted by sexual predators and can be subject to abuse and maltreatment at school.

CONFLICT/WAR

- for every child killed in armed conflict, three are injured and permanently disabled
- 40 per cent of 26,000 persons killed and injured by landmines every year are children
- more than ten million children are psychologically traumatised by armed conflicts.



Handout 5

COMMON MYTHS ABOUT INCLUSION

HOW TO USE THIS HANDOUT

Use this handout with the following activity:

- **Excuses excuses**

A whole range of reasons are given when you ask why disabled people are not travelling on the 'main road' of development. Here are some of the most commonly held views – along with informed common sense responses.

'We need to sort out the problems of "normal" people first'

Disability IS normal. Disabled people are in every community. It's an expression of the diversity of the human race. Our perceptions are distorted by social norms which keep disabled people out of the public arena, and by the narrow vision of beauty presented in media images. Good development work challenges conditions which exclude the oppressed – disabled people are among the most oppressed.

'It's not cost effective'

Including disabled people is often seen as an 'extra'. It happens in an ideal world. It's a luxury. Saying 'we only have enough money for the basics, so we can't afford to include them' denies the reality that disabled peoples' needs ARE the basics. It doesn't necessarily cost much more to include them in development, especially if it is planned from the outset. For example, physical accessibility is estimated to account for additional construction costs of between 0.1 and 3.0 per cent.

'There aren't many disabled people here, so it's not an issue'

Disability is treated as a specialist area, often because of the misconception that their number is insignificant. This myth arises because many disabled people are invisible. In reality, they may be hidden away due to stigma, or are excluded from meetings because of a lack of access. If aid workers don't see disabled people in their work, they tend to assume they don't exist in the community. Disability affects the family as well as the individual, and they also face discrimination and increased poverty.

'We don't "do" disability'

Disabled people are often regarded as a distinct target group for separate programming. So some agencies specialise in disability and others do not, thinking their needs are already being dealt with. However, only a small

Handout 5

number of disabled people participate in programmes of specialised agencies or targeted work. By not including disabled people, mainstream programmes fail to address the needs of a group who account for at least ten per cent – and perhaps up to 20 per cent – of any given population.

'We don't have the skills'

Working with disabled people is not significantly different from working with any other group. Many needs are the same. Sometimes the approach to meeting them is different. Disabled people themselves are the best experts and can often suggest modifications to make things work for them. It's largely about changing attitudes. Sometimes low-tech simple solutions can have a major impact on accessibility for disabled people.

'Let's create a special programme'

It's unrealistic to expect a single specialist intervention programme to address all the needs and rights of all disabled people – who are a diverse group. Many of these needs are shared by other people and are not disability-specific. They are best addressed within the framework of the whole community.

Perhaps you have come across other reasons why inclusion of disabled people isn't happening – what should a common sense response to them be?

Handout 6

A GUIDE TO DISABILITY ORGANISATIONS

HOW TO USE THIS HANDOUT

Use this handout with the following activities:

- **Reality check**
- **Excuses excuses**

A QUICK TOUR

Disabled people have been excluded from most decision-making processes. Families, communities – and development organisations – have tended to decide on their behalf, even when it directly affects their lives. That could be about undertaking physical therapy, having surgery or being sent away to a ‘special needs’ school.

As a result, they’re rarely consulted or involved in development planning. Few have the opportunity to take up leadership positions. In response, a Disability Movement has been growing around the world. Its aim is to represent the voice of disabled people and lobby for greater inclusion. Conditions vary from country to country. But often there are national organisations for many of the main impairment groups – with branches or committees in towns and villages. If the movement has been established for a while, there may also be a federation or union representing all disabled people in national level policy-making.

Each organisation has a part to play, to ensure disabled people benefit from development. All can be important resources for meeting the needs in your region. However, contacts for consultation about inclusion must be with disabled people themselves – through self-help groups, DPOs or national and international bodies.

DISABLED PEOPLE’S ORGANISATIONS (DPOs)

- are organisations **OF** disabled people
- many represent people with a particular impairment
- in countries where the disability movement isn’t strong, there may only be two or three impairment groups represented
- some national level DPOs are known for their lobbying, such as the National Union of Disabled People Uganda (NUDIPU), and Federation of Disability Organisations in Malawi (FEDOMA)
- some are represented at regional and international level, like the Southern Africa Federation of the Disabled (SAFOD) and Disabled People’s International (DPI)
- many are small, relatively weak in capacity and focus on meeting the immediate needs of their members

Handout 6

- the most important aspect of DPOs is their ability to understand the needs in their locality and to mobilise disabled people
- with support, DPOs can be effective partners in community development programmes for mainstream initiatives.

SELF-HELP GROUPS

- **are groups of disabled people not yet registered as DPOs**
- tend to be more common in rural or semi-urban contexts where DPOs have yet to reach, or for groups who lack the resources to formally apply for registration
- play an important role at local level in connecting disabled people with each other
- often offer social support and can be mobilised to provide economic assistance in emergencies
- can be an important link between disabled people and community development programmes, and should be sought when carrying out assessment activities.

DISABILITY NON-GOVERNMENTAL ORGANISATIONS (NGOs)

- **are organisations working FOR disabled people**
- include large international NGOs like SightSavers, Leonard Cheshire Disability, CBM, Sense International, Sue Ryder Care, Handicap International and Action on Disability and Development
- some specialise in particular impairments, some are more focused on building the capacity of disabled people and their representative organisations
- numerous national NGOs target disabled people specifically, e.g. Uganda Foundation for the Blind, and Association for People with Leprosy in Angola
- include faith-based charities supporting special needs schools or vocational training centres or working to help produce artificial limbs
- in many cases medical/rehabilitation needs may be primary support focus
- many are moving to rights-based approaches.

Stories from the road



20 million people who need a wheelchair
don't have one

Stories from the road

THE HISTORY OF 'TRAVELLING TOGETHER' AND HOW THE COURSE HAS SPREAD FAR AND WIDE

Sue Coe, Senior Disability Programme Adviser, World Vision UK



November 2005 – I found myself tracing circles with my finger on the desk. Drawing this imaginary diagram was my hesitant attempt to break through our language barrier. I was needing to explain to an experienced Francophone African programmes director why World Vision UK wouldn't be able to support his disability project, which was clearly not based on the 'social model'.

So out of thin air I created a large circle representing 'society'. A smaller circle represented 'disabled people'. Directional arrows followed, to describe the differences between medical, charity and social models of disability. I prepared myself for his challenging feedback. But it never came.

'If that's the case,' my African colleague responded, *'we should be adopting the social model principles and the project needs complete redesign'*. I was both amazed and delighted. It was the first time I'd used these circles and directional arrows to explain the concepts. And it worked.

That was delivering the concepts in a one-to-one encounter. But what happened when such ideas were conveyed to a whole group of individuals – all experienced programme staff? We found that out when nearly 20 people convened in a meeting room in Buckinghamshire, England seven months later. It went much better than expected.

I'd been a little nervous about it. I was particularly concerned about how the Game Of Life activity would be received. It went very well, as it turned out. In fact, it left a marked impression on my programming colleagues. This pattern has been repeated on many occasions at subsequent courses, experienced by both Lorraine and myself. Feedback from participants on that first course delivered by Lorraine Wapling included:

- very accessible workshop;
- excellent trainer;
- great to learn so much without my brain hurting;
- timing of workshop couldn't have been better, individually and within World Vision partnership;
- good fun games to help think of existing attitudes;
- very practical;



Deaf children enjoying school in Botswana
photos: L.Wapling

'The training course has consistently 'hit the mark' wherever it's been delivered. It's a tool to achieve change.'

- kept things fairly simple;
- good, practical, and easily transferred activities and techniques.

So how did this concept emerge? How did a simple course come about, which highlighted a much neglected area of mainstream international development work – the inclusion of disabled people? For already it has been delivered to more than 2,500 people working in at least 28 countries.

It's a development story in its own right. But there's one consistent theme. The course has consistently 'hit the mark' wherever it's been delivered. It's a tool to achieve change. Most importantly, it addresses negative attitudinal issues most of us carry when working with disabled people.

People who've received the training spread the word in areas relevant to their own contexts. We encourage non-disabled people to co-deliver the course with disabled people, who illuminate and bring important authenticity, experience and knowledge to training delivery.

Those who've been trained claim the course is providing World Vision staff and project partners with a common, simple conceptual language of understanding about development – which should include disabled people as equal participants, not passive welfare-beneficiaries.

First steps

THE CHALLENGES THAT LAY BEFORE US



Sue and Lorraine
photo: World Vision Ethiopia

I started as Disability Adviser at World Vision UK in September 2005. I'm a development worker who's moved into disability inclusion work as a result of professional and personal experiences over 15 years. I was quickly joined by Hitomi Honda as World Vision Global Centre Disability Adviser.

Our employment represented increased investment in World Vision (championed by World Vision UK at that time) into translating a policy commitment of inclusion of disabled children and adults in all World Vision's work into practice on the ground. This commitment was building on work started by World Vision UK-based staff Jane Betts and Jonathan Flower.

In late 2005 there were 26,000 staff globally in World Vision. That figure is now over 40,000. Commitment to disability inclusion was expressed across the world by a grassroots staff network, plus senior level support from some influential quarters – including World Vision UK Chief Executive Charles Badenoch.

Disability had just been designated as a cross-cutting theme in World Vision's new global monitoring and evaluation framework. All new National Office projects were urged to look at issues on disability as part of programme assessment processes.

The reality I found was different. Despite being supportive in principle, most staff across World Vision saw disability inclusion as an extra pressure. It was a burden for their already overcrowded work portfolios. They were working hard to do their best and deliver on their responsibilities. But they felt this issue was difficult, specialised, time-consuming and an additional 'sector'. It was perceived as a little overwhelming.

Many had great nervousness about approaching disability inclusion, partly for fear of doing or saying 'the wrong thing'. It also quickly became clear most didn't have a clear conceptual understanding of what was meant by 'disability inclusion'. I found significantly different viewpoints among a wide range of staff in the UK and National Offices on what this actually meant in practice.

Two specific discussions in autumn 2005 help illustrate the reasons for the course. A World Vision UK middle manager said he couldn't see how he would/should employ a disabled person, unless they could demonstrate their ability to carry out all tasks – including international travel requirements – as they stood.

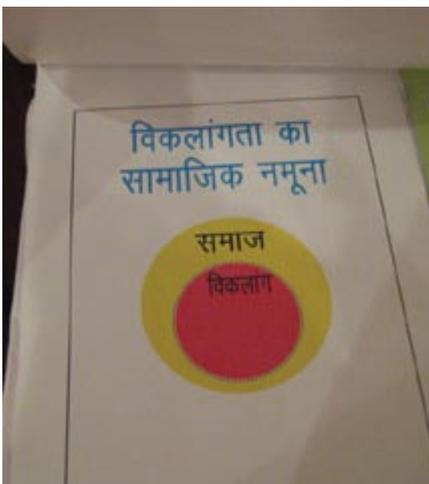
His bravery/brazenness was shocking. But it revealed a sentiment I suspected many quietly held, yet few would feel it acceptable to say out loud – partly as such discrimination is illegal under UK employment law! However, it helped uncover the need for more work in this area.

Hitomi was having similar conversations with others. The discussion with the African director – as described earlier in this section – also made me realise we did not have the capacity to have the same conversations with everyone in a partnership of nearly 30,000.

We needed to see significant change. But helping bring about meaningful transformation felt like an impossible task. I could clearly see that including disabled people was an extension of what World Vision already aspired to – inclusive development, especially for the most marginalised.

So a key challenge seemed to be to tackle staff attitudes as a prerequisite of confronting anything else. Otherwise, programming activities would have little meaningful impact. It seemed like an 'Everest-sized' mountain that we had to climb.

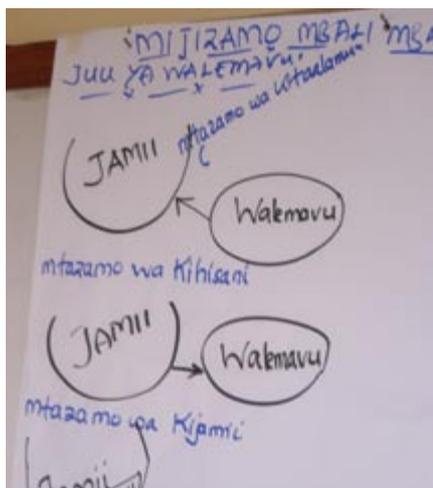
Then it struck me. Finding an effective way to communicate the core principles – that would equip staff to address attitudes, express principles and share them with others – could significantly help the agenda 'roll out' faster. It would be a ripple effect. The idea for a one-day training course gained momentum.



Social model diagram in Hindi
photo: H. Williams

Moving on

THE PRINCIPLES BEHIND THE COURSE'S DEVELOPMENT



Disability models in Swahili
photo: C. Donald

I am a non-disabled person. So for me, an important principle was that the course should be delivered by a disabled person. I decided to approach Action on Disability and Development (ADD) for support in designing the programme.

ADD had more than 20 years' experience in empowering Disabled People's Organisations across a range of development contexts in Africa and Asia. I asked Lorraine Wapling, then a Programme Co-ordinator at ADD, to design a course with me. Lorraine is an experienced development worker with a training/teaching background. She is also deaf. I produced a brief on what I wanted a one-day course to achieve:

- 'de-mystifying' people's fears about disability inclusive programming – people perceive it as difficult/specialised and, in some cases, not their job;
- a clear understanding of the three models of disability as an important foundation for realising why the social inclusion approach is important;
- fun and enjoyment – many people can feel daunted/deterred to attend training on disability issues as they perceive it to be a 'tough' subject;
- interaction, addressing the diverse range of learning 'styles' present in any training room as people have their own preferences;
- replicability – to enable participants to onward deliver the course;
- practical guidance on how to approach the effective inclusion of disability issues in development programming;
- the training room to be a disability-inclusive environment to let participants experience its benefits and so encourage them to onward deliver the course using the same principles;
- professional quality course to help push disability issues higher up World Vision's global programming agenda;
- attractive course that could be of interest and use in broader mainstream international NGO and government circles.

Most of the initial discussions were how to interpret this extensive and ambitious agenda in practice. We wanted to construct a 'flow' of activities that facilitated maximum attitude change in just a day – and in a language that would effectively 'speak' to experienced and busy programming staff.



Inclusive class in Cambodia
photo: L.Wapling

'I didn't want people holding back because of a fear of what is acceptable – or not – to say. It is extremely important to have complete honesty in the training room.'

I was very happy with the activities Lorraine developed after these extensive talks. However, I recognised what would be delivered was experimental so was unsure how it might be received. Lorraine had her own perspective.

'It's hard to remember how innovative the idea was,' said Lorraine, 'since I've now delivered the training successfully to so many different groups of people. But thinking back over the whole experience, I'd probably say at the time I didn't really appreciate how powerful this series of activities would be.'

'When Sue and I talked together about what was needed, many thoughts and options came to mind. We certainly wanted to focus on changing attitudes. I strongly felt this was the single most important barrier to the lack of take-up of disability inclusive programming by mainstream development agencies.'

At the time there was no international framework. The United Nations Convention on the Rights of Persons with Disabilities was still not 'on the books', as Lorraine put it. 'But I felt strongly disability was essentially being ignored as an issue,' she said, 'because most development practitioners had no personal experience of it. They still regarded it largely as a medical/rehabilitation issue.'

'What I wanted as the foundation of the course was the opportunity to challenge that mindset. I wanted to lead people through a process where they would come to experience issues relating to disability in a way they could relate to.'

Lorraine felt strongly that she didn't want to 'simply lecture' – but to give people the chance to question their own thoughts and beliefs. 'It would therefore be a transformational process,' she added, 'because it was attitudes I wanted to challenge. However, I had no idea whether it would work or not!'

Course activities partly drew on what had been published in the Oxfam/ADD (2003) *Disability, Equality and Human Rights* training manual. But careful structure and new activities were needed to work for World Vision UK programming staff.

Getting on the road

THE FIRST COURSE DELIVERY



The course was first delivered to 17 World Vision UK programming staff in an unassuming venue on the outskirts of Milton Keynes, Buckinghamshire, England.

Lorraine can still remember running that first workshop. 'It was nerve wracking,' she said. 'There were so many reasons why people might reject what I was asking them to consider – seeing disabled people as legitimate, "regular" participants of their programming rather than occasional beneficiary "targets".'

'Why should people suddenly change now? How would people react when I revealed the possibility that they had consistently excluded people because of their own prejudices and preconceptions? This wasn't going to be easy.'



'There were a number of experienced development professionals in the room. I was expecting them to take part in a whole range of interactive activities. I wasn't giving them a fact-filled PowerPoint enhanced seminar.' Lorraine realised somehow she was going to have to persuade her audience that the traditional development approach might not be the best way of doing things. 'Would I even be taken seriously?' she asked.

But things went well from the first activity. 'Guessing Game was the perfect choice for a warm-up exercise,' said Lorraine. 'Not only did it set the tone for rest of the day – that this was going to be interactive, fun and exploratory – but also it ensured people got talking.'

'I found the models activity very easy to manage. It flowed perfectly from Guessing Game. Asking people to think about words associated with disability did produce some quite disturbing answers for me as a disabled person. But the purpose had been achieved.'

'I didn't want people holding back because of a fear of what is acceptable – or not – to say. It is extremely important to have complete honesty in the training room. The placing of their words under the appropriate model heading certainly provoked strong discussion and, as I had hoped, helped me to assess how well people had grasped the concepts.'

First training course – June 2006
photos: S. Coe

'The most dramatic turning point... was the impact of the Game of Life.'

Probably the most dramatic turning point for Lorraine was the impact of the Game Of Life. 'I had no idea this would prove to be such a popular and powerful activity,' she said. 'I was nervous about asking people to volunteer as "role models" and wasn't sure the group would fully engage with this activity.

'I felt quite strongly the message it was designed to show was a really important one. I was just unsure whether this was the right medium for delivering something so serious. Once again, though, my fears were dispelled. Almost immediately people began to engage with the scenario.

'People were more than happy to volunteer. The ensuing "arguments" and discussions proved to be hugely important. The shock among participants at the end of the exercise was palpable. People genuinely began to take a long hard look at how development contributes to exclusion. I have seen this reaction hundreds of times since in response to this activity.'

That first workshop gave her a great deal of confidence. 'Experienced development professionals were willing to engage in an interactive workshop and question what they'd been doing,' said Lorraine. 'It was possible to bring about a change in attitudes in just one day.

'It was possible to bring about a change in attitudes in just one day.'

'It was never designed as a workshop on how to completely mainstream disability. That's a much bigger issue. It was mainly to challenge how people perceived disability in development. It worked. That then enables them to start reinterpreting their work, but with a new understanding and inclusive attitude towards disabled people.' Lorraine found the activities and timings were just right, and has varied things little since. 'It still works as it did on that first delivery,' she concluded.

Fellow travellers

HOW 'TRAVELLING TOGETHER' HAS BEEN ADOPTED AND APPLIED



Self-help group meeting in Cambodia

The most immediate change I noticed was the discussions I subsequently had with the people who had attended – all programming staff. Those talks were more productive and creative. We moved forward faster on thinking about how to promote disability inclusion to our link World Vision National Offices.

I suddenly felt I had allies rather than 'lobby targets'. I no longer needed to explain or justify the social model approach. Programme Officers took the initiative and started to deliver parts – or all – of the course on their visits overseas.



Lorraine with Maasai men in Tanzania
photos: L.Wapling

Sometimes they only even 'checked in' with me on what happened after the event! The training fitted well with World Vision's decision to make disability one of six key 'cross-cutting' themes. Feedback said the training course had been practical and useful. Most importantly, we heard it was being replicated by programmes staff.

It also came out well in a survey of World Vision UK programme staff in December 2006. Of 25 training courses delivered during 2005/6, ours had been the most equally enjoyed – with two others – and had been top ranked for 'being the most used course'. Most people had used the course or contents since attending.

So how has *Travelling together* been used in different contexts? There are quite a few stories to share about that. Some are told here. For the sake of not making this part of the book a lengthy novel in itself, I'm happy to share others on request.

ETHIOPIA

Ethiopia is the second largest National Office in the World Vision Global Partnership, and the largest in Africa. Huge work was invested by the advocacy staff in Ethiopia to ensure all participants – 102 from Ethiopia and 12 from 6 other countries, all in significant positions of responsibility – made it to the training organised in three different groups. In such a large and diverse country, this was an achievement in itself. Once the course started, the significance was the high retention rate. All people returned from their breaks on time – and didn't disappear from the training room during the day (I was informed this was not generally the case!).



Ethiopia training



the group discuss "what is disability"

"You have shown us what we ourselves have neglected, thank you all"
participant in Ethiopia



the group participate in the "Game of Life" activity

"The Game of Life was a wake up call for all of us to see the reality on the ground for disabled people and it left a mark on everybody's mind"

"The method forced us to look into ourselves and look for the solution in ourselves."

Lydia Mesfin, World Vision Ethiopia Advocacy Manager

The course was subsequently onward delivered to over 700 more people in Ethiopia – World Vision staff, partners, disabled people and government staff across all regions of operation. The course was also delivered to 55 Members of Parliament as part of a three-day inclusion effort, and 84 trainees as a pre-cursor to WATSAN inclusion training. All Ethiopian courses have been delivered with disabled people from their national disability movement.



Group work



Lorraine and Sue explaining models

"The material developed is really helpful, practical and relevant to the situation of Ethiopia. I appreciate the content and the people who worked on it."

Mr Sahilu Kassahun, President, Ethiopian Federation of National Associations of Persons with Disabilities



India training - the wall

photos: H. Williams

"Our eyes were opened to being sensitive regarding issues related to disability"
participant in Chennai, India

"I'll start to talk about disability in all my activity with community people"
participant in Delhi workshop

INDIA

Having heard of what happened in Ethiopia, the National Director of India, Jayakumar Christian, invited Lorraine to bring the course to his country. India is the largest National Office in the World Vision family, so this was a very significant invitation. The course was delivered to 16 senior staff at the Head office in Chennai, and 50 project staff working across a range of projects in the country. The training was positively received with such comments as:

- liked the Game of Life very much;
- the social model was excellent;
- all the sessions were very lively;
- sessions were simple and powerful;
- the course covered disability very simply and effectively;
- we never felt tired;
- disability is all about our attitude – I will change in this area.

Since the course was delivered, plans and activities have developed both in the Chennai Head Office and across programming work in the northern part of India. Other partners have been invited to train, and the course extended for WV India's needs, with staff feeling confident to approach and select local partners that work on social model principles.



Game of Life - Chennai senior management team

UGANDA

World Vision Uganda had already started the process of working on disability inclusion guidelines when two staff from their advocacy department attended the training in Ethiopia. It significantly helped their understanding of the core issues and in moving forward on the inclusion guidelines. They formed a committee with a range of Disabled People's Organisations to help that journey.

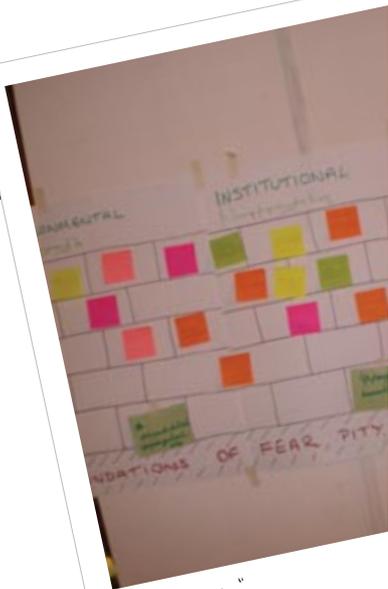
The one-day training course formed part of the publication, along with a range of information on the situation in Uganda provided by different committee members. More than 60 people attended the launch event – including Government, media, DPO representatives and NGOs.

Subsequently, the Ministry of Gender, Labour and Social Development have used the training and guidelines for their own purposes at field level. The next stage is to develop a network of trainers among the DPO committee to deliver the course to a range of agencies in Uganda.



A copy of the WV Uganda training manual presented by Hon Ndeeki Alex (right) - Member of Parliament and of UNAD (Uganda National Association of the Deaf)

Photo: WV Uganda



'the wall'



Suren

photo: S. Coe

ARMENIA

Suren Maghakyan is a disabled man who runs an NGO in Stepanavan, northern Armenia. He has been delivering disability awareness

training for a number of years. He took part in the course when it was delivered to programming staff at World Vision Armenia's offices at Yerevan. The trainer had initially learned about the course when it was delivered the previous year in Angola, by a trainer who attended the first training course in the UK (demonstrating itself the 'onward training' methodology built into its design!). *Travelling together* had an impact on Suren in two ways:

- his perception of himself as a disabled person – he found the training very empowering and realised the social model of disability reflected and expressed his own situation;
- the delivery of his own training – he translated all the handouts into Armenian, and abandoned his course in favour of this one. He has now delivered the course in a range of contexts, including bilateral government donor staff and school children – currently to over 200 people.

photos: S. Kambarami



Participants in Armenia training

'We identified ways of inclusion of disabled persons into programming and therefore into society'
trainee in Armenia

'We became familiar with community stereotypes and new opportunities of collaboration with disabled people'
Training participants - Programme managers and disabled people

UK DFID GOVERNMENT STAFF

Travelling together has also been delivered in full to two overseas DFID offices – Nigeria and Malawi. Parts of the course have been used during seminars and discussions with DFID UK advisers on a number of different occasions. Having the support and participation of office chiefs and senior staff alongside more junior ones made quite an impact. It enabled everyone to discuss disability using the same concepts, but also brought all the staff together in ways not commonly experienced by DFID.

It enabled the cross-cutting nature of the discussions to come through, and helped locally appointed staff to talk more about some key cultural issues affecting development. Since the training, some evidence of disability-sensitive programming has begun to emerge – and interest is growing from other countries where DFID has in-country presence.



Participants in Malawi DFID office training

photo: L. Wapling



BOND DDG event, Game of Life.



BOND DDG group speakers, all disabled people except Charles Badenoch.

photos: BOND Disability and Development Group

SENIOR STAFF FROM THE UK'S BIGGEST INTERNATIONAL DEVELOPMENT AGENCIES

On 3rd December 2007, on the International Day of Disabled Persons, the UK inter-agency BOND Disability and Development Group organised an event targeted at senior management in UK international NGOs and funders. More than 50 people attended. The event featured platform speeches from disabled people, an MP, DFID representative and World Vision UK's Chief Executive Charles Badenoch.

Part of the event was a training session comprising of Guessing Game and Game Of Life. Although unusual to deliver training activities in a plenary speech-led event, the 'taster' sessions had impact and reinforced the points made in the speeches. One international NGO Operations Director used the information immediately to review the annual planning process of his organisation.

As a direct result of the BOND DDG event, an invitation came to present a slot on disability inclusion to UK Disaster Emergency Committee trustees meeting several months later. The significance of this invitation was that the DEC trustees mainly comprise the Chief Executives of the 12 member agencies – who largely represent the biggest international development organisations in the UK. At the end of the session the trustees acknowledged its impact, with two of them pledging immediately to examine the implications of disability inclusion for their organisations.

TANZANIA – MAASAI COMMUNITY

Lorraine led some basic disability awareness training as part of a general community needs assessment process with a Maasai community of approximately 200 people in the Tanga region of Tanzania. 'During our initial village visits,' she said, 'we noticed a number of disabled people and wondered how to encourage the community to include them more in decision-making forums.'

'I chose to run Game Of Life – largely because we were deep in the bush and had no access at all to any paper or pens. But I also picked that activity because it's such a quick and visually powerful way of reminding groups of people about how excluded disabled people can be. As always, it proved to be a lot of fun.'

'It was particularly interesting and encouraging to see both the men and the women fully engaged and participating together. In all other discussions we had only ever encountered groups of men or women. It enabled us to talk openly about disability and highlighted some of the inequalities disabled people face. It was certainly a talking point long after we left!'



Maasai community training

photos: B. Downie

Road ahead

WILL YOU JOIN US ON THE JOURNEY?



Sue Coe and Lorraine Wapling

We celebrate all of these successes. But however happy people have been about *Travelling together*, it's not a 'miracle' fix-all. Once it's been delivered, disability inclusion won't 'magically' happen. Policy development, office champions, senior level commitment – all of these things are needed.

What this course aims to do is tackle attitudinal barriers in a direct but non-threatening way – so people can draw on their own professional and personal experiences and understand why disability inclusion is a key development issue. Essentially it's an extension of what they already are – or should be – doing.

It's simple. Most estimates place disabled people as 10-20 per cent of any population group. How can such a large number of people be ignored by any development agency – including World Vision – if we're taking our agendas seriously? For we all need to travel together on the main road of development.

If you use this training course in your work, Lorraine and I very much encourage you to share your experiences with us – we'd be delighted to hear about them, both good and challenging.

Resources



90 per cent of people with intellectual impairments will experience sexual abuse, often in childhood

Introduction

There are many resources on disability inclusion. Many have been developed over a number of years. Most are effectively untested in 'field' situations.

In this section, we point you to the best places for resources relevant to your situation. We also give you recommendations from both ourselves – and from some of the leading experts – on some of the available resources.

As authors based in the UK we always use the terms 'disabled people' and 'disabled children' in our writing. However, in other cultural contexts the terms 'people with disabilities' and 'children with disabilities' are used. So you will see reference to both terms in this section.

We stress that **non-discriminatory attitudes underpin all practical programming and are the single biggest factor facilitating inclusion.** Very often people focus on a 'checklist' mentality. If workers and partners understand the principles of the social model, they can apply these principles to their setting and quickly see significant progress.

The section uses the Millennium Development Goals (MDGs) framework as an introduction to different topics and provides practical resources, or links to where those are available. The UN Convention on the Rights of Persons with Disabilities is an important guiding document, a summary of it is given under the MDG Goal 8 section. There is also a section giving guidelines and practical notes from information developed in World Vision and elsewhere.

Most of the resources listed are freely available to view and download from the internet. 'YouTube' clips of work are also starting to increase in popularity. There

are a few general websites that are 'hubs' of pooled information that you can research and source information on specific areas. These are:



Source is an international information support centre designed to strengthen the management, use and impact of information on health and disability. Source provides free access to over 25,000 resources relating to the management, practice and communication of international health and disability issues. It includes both published and unpublished materials, many originating from developing countries.

Source is a collaborative venture of the Centre for International Health and Development, Handicap International and Healthlink Worldwide.

UN Enable – www.un.org/disabilities

A wide ranging source of information, research and up to date discussions on the UNCRPD.



International Disability and Development Consortium (IDDC) –

www.iddconsortium.net

For a selection of resources, programmes and networks in disability and development. See also their MDG initiative at **www.make-development-inclusive.org** and **www.includeeverybody.org**.

International Disability Alliance (IDA) – www.internationaldisabilityalliance.org

For information and resources linked to the promotion and implementation of the UNCRPD.

Disabled Peoples' International (DPI) –
www.dpi.org

A global network of national organisations and assemblies of disabled people, established to promote human rights of disabled people through full participation, equalisation of opportunity and development.

The Disability Rights Fund (DRF) –
www.disabilityrightsfund.org

For information and sources of direct funding for DPOs.

The Enabling Education Network (EENET) –
www.eenet.org.uk

An information-sharing network on issues linked to inclusive education.

Disability KAR – www.disabilitykar.net

A UK Government funded programme that ran from 2003-2005 producing a broad range of research, a large proportion of which was conducted by disabled people.

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Setting the scene

THE MILLENNIUM DEVELOPMENT GOALS AND PEOPLE WITH DISABILITIES

Diane Mulligan and Kate Gooding

WHAT HAS BEEN THE IMPACT ON POVERTY REDUCTION OF THE MDG PARADIGM?

The Millennium Declaration committed governments to *'making the right to development a reality for everyone and to freeing the entire human race from want'*: the right to development is clearly universal. However, apart from Goal 2, the targets for 2015 are not measured by universal achievement and define aspirations only for proportions of the world's population. Moreover, apart from women of reproductive age and children, the Millennium Development Goal (MDG) framework does not make any reference to marginalised groups. With the focus only on aggregate results, national progress can be made without any change in the situation of the poorest.

This framework of proportions and averages means policy-makers may focus on those who are easiest to reach in an effort to reach headline MDG targets as efficiently and quickly as possible. Most significantly, the target of halving US\$1/day poverty by 2015 could be achieved by concentrating on the 'least poor' and excluding action to address the most marginalised (Chronic Poverty Research Centre, 2008). Attention only to averages and 'easier' groups would jeopardize the ultimate goal of poverty eradication, and may result in even more intractable poverty in 2015 (Chronic Poverty Research Centre, 2009).

These partial targets mean the MDG framework is inherently flawed because it does not meet the needs of the world's poorest and most marginalised populations. The lack of specific attention to marginalised groups in the targets and indicators creates a real danger that efforts to achieve the MDGs will push some of the world's poorest people to the periphery. In particular, the exclusion of a category of people who cannot access mainstream social, economic and political life, and have limited access to almost all areas of development – people with disabilities – is extremely problematic.

Disability is both a cause and consequence of poverty (DFID, 2000), and poor people themselves describe people with disabilities as among the most excluded 'poorest of the poor' (Narayan & Petesch, 2002). According to the World Bank, 20 per cent of the world's poorest people are disabled (UN Enable, 2009), yet disability is not mentioned in any of the 8 MDG goals, the 18 targets, or the 48 indicators. People with disabilities are also largely absent from international and national strategies and action plans for poverty reduction. As the former President of the World Bank, James Wolfensohn stated in 2002: *'Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015'*. The UK Department for International Development (DFID) also recognises that *'Disability*

is a key threat to reaching the Millennium Development Goals' (Lowcock in DFID, 2007) and 'challenging exclusion is central to reducing poverty and meeting the MDGs'. Thus, promoting the inclusion, rights and dignity of people with disabilities is central to poverty reduction and to achieving human rights (DFID, 2007).

Sightsavers has also produced its own research that demonstrates the relationship between blindness and poverty (Gooding, 2006; Gilbert et al, 2007). The life chances of People with disabilities are relevant to all eight of the MDGs, making it an issue central to reducing poverty. For example:

MDG 1 Poverty reduction: Although poverty is not just about economics, people with disabilities often struggle to find opportunities to earn income due to discrimination in education and employment. In areas of Bangladesh, the employment rate of people with disabilities is less than a quarter of those without a disability (Chowdhury, 2005).

MDG 2 Education: Of the 75 million children of primary school age out of school, over a third have a disability (UNESCO, 2009) and yet the inclusion of children with disabilities in mainstream education has been shown to be successful (Bhatti, 2007).

MDG 3 Gender equality: Women who are disabled face discrimination because of their impairment, but also face discrimination on the grounds of their gender. This double discrimination has been well documented in development policies (Abu Habib, 1995). Women with disabilities are also more likely to be subjected to violations of human rights than women without disabilities (Braathen, Hoem & Kvam, 2008).

MDG 4 Child mortality: In some developing countries, mortality rates for disabled children under five can be as high as 80 per cent, even in countries where overall under-five mortality is below 20 per cent (DFID, 2000) and disabled children are less likely to receive standard immunizations (Groce, Ayorla & Kaplan, 2007).

MDG 5 Reproductive health: Women with disabilities face particular challenges in accessing reproductive health education because they are not considered sexually active people (Maxwell, Belses & David, 2007), nor do they receive timely antenatal care should they choose to have children (Sobsey, 1994).

MDG 6 HIV: All risk factors associated with HIV are increased for people with disabilities (e.g. sexual activity, rape, substance abuse), yet they are less likely to be included in outreach or treatment activities (Groce, 2004).

MDG 7 Ensure environmental sustainability: Of all poor people, people with disabilities have the least access to safe water and sanitation facilities and this contributes to keeping them poor and unable to improve their livelihoods (Jones & Reed 2005).

MDG 8 Develop a global partnership for development: Article 32 of the UN Convention on the Rights of Persons with Disabilities explicitly states that international cooperation (partnerships) and development programmes are 'inclusive of and accessible to persons with disabilities' (Art 32 [1]).

The lack of knowledge and understanding about the extent of exclusion of persons with disabilities among decision-makers, donors, international agencies, governments and other development actors, and the

lack of recognition of disability as a crosscutting issue has resulted in the low priority given to disability within mainstream international development. Some recent progress reports on the MDGs have made commitments to include people with disabilities in poverty reduction strategies, but have subsequently failed to provide budgets to implement the programmes (DFID, 2007) rendering the process ineffective. In contrast to disability, gender has become an issue that has been prioritised (although not realised), and seen as essential to meeting MDG targets.

ONE MAJOR GLOBAL PROCESS SHAPING DEVELOPMENT UP TO 2015 AND BEYOND IS THAT OF CHANGING DEMOGRAPHICS

The world is experiencing an unprecedented demographic transformation. By 2050 the number of persons aged 60 years plus will increase from 600 million to almost 2 billion and the proportion of persons aged 60 years and over is expected to double from 10 to 21 per cent.

The increase will be greatest and most rapid in developing countries where the older population is expected to quadruple during the next 50 years (UN, 2002). Because the incidence of impairments tends to be higher among older persons, there are major policy implications for this group of people in relation to the MDGs. In addition, *'improved medical care means higher survival rates for individuals who are born with a disability or acquire a disability through illness or accident'* (UN, 2008a). The increasing numbers of people with disabilities needs to be factored into plans for poverty reduction until 2015 and beyond.

The United Nations Convention on the Rights of Persons with Disabilities came into force in May 2008. The Convention has already been signed by 139 countries and ratified by 53. The Convention defines disability both as a human rights and a development issue. Article 32 articulates that countries that have ratified the Convention will ensure that international cooperation, including international development programmes, are inclusive of, and accessible to people with disabilities. The implications of this Convention – and other human rights frameworks – must be substantially reflected in future development frameworks.

We are not advocating for the MDGs to be re-written or for a separate MDG to be established for people with disabilities. However, incremental changes, including disaggregation of data and realignment with the Convention would not be a major undertaking. Campaigns to include people with disabilities in the MDGs have already been established (www.includeeverybody.org), and an expert group meeting has already taken place within the United Nations on adjusting indicators to incorporate people with disabilities. There are even clear examples and guidelines on indicators designed to identify links between the MDGs and the new Convention (UN, 2008b). This progress must be continued and strengthened to 2015, and built into future development frameworks.

Development policy-makers and practitioners do not have to undertake the inclusion of persons with disabilities alone. The worldwide disability rights movement has established national and international disabled people's organisations and networks. These organisations advocate for the involvement and participation of people with disabilities in all levels

of planning for development, as well as providing guidance and jointly working with high-level development personnel. If people with disabilities are not included in the process then people with disabilities living in poverty will be further marginalised and more likely to experience chronic poverty.

Therefore, the framework (Convention) and mechanisms (UN dialogue) for the inclusion of people with disabilities are in place, and the willingness of people with disabilities to engage with decision makers exists. We now need those responsible for the MDG monitoring and evaluation processes to explicitly state that disability specific data collection and analysis

be undertaken in order to ensure that people with disabilities in developing countries do not remain as a statistical afterthought. Once the evidence on exclusion exists, then people with disabilities need to be included in future development frameworks that prioritise the human rights of the most marginalised and poorest people.

REFERENCES

see original paper –
http://www.sightsavers.org/learn_more/reports_and_research/10990.html

The Millennium Development Goals (MDGs) and disability inclusion

MDG I – ERADICATE EXTREME POVERTY AND HUNGER

DISABILITY AND POVERTY

Lorraine Wapling

Disabled people share the same problems as the non-disabled poor but they experience poverty more intensely. Attitudinal and structural barriers limit their opportunities to escape poverty. A strong cycle of disability and chronic poverty exists – those who are poor are more likely to become disabled and those who are disabled are much more likely to be poor (see diagram over page).

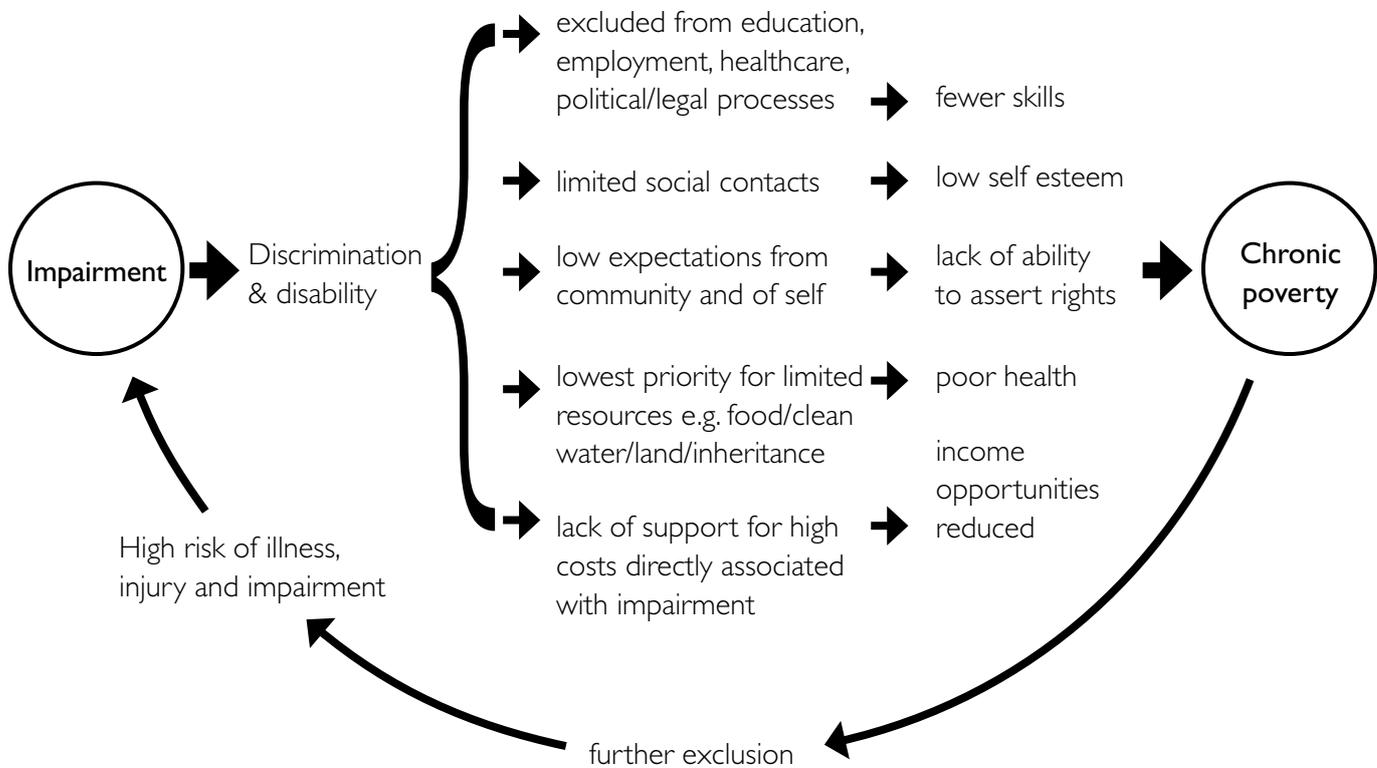
THE CYCLE OF DISABILITY AND CHRONIC POVERTY

Poverty is both a cause and consequence of disability. They reinforce each other, contributing to increased vulnerability and exclusion. The majority of disabled children and adults find their chances of going to school, working for a living, enjoying family life, and

participating as equals in social life are severely restricted – not because of their impairments but because of the attitudes and discrimination faced from communities. Disabled people who are denied formal education then find it hard to obtain jobs, access public services or participate in community development, thus segregating them further from society and making them dependent on the support of others.

But the cycle goes beyond disabled people. Their families often don't have sufficient income to meet basic needs. Inadequate shelter, unhygienic living conditions, lack of sanitation and unclean drinking water combined with poor access to health facilities are all leading causes of disability. This means communities which have high levels of chronic poverty are also likely to have high rates of disability.

DISABILITY/CHRONIC POVERTY CYCLE*



* based on R.Yeo: Chronic Poverty and Disability Cycles

MDG I – ERADICATE EXTREME POVERTY AND HUNGER

INTRODUCTION TO LIVELIHOODS AND DISABILITY INCLUSION

Sue Coe

The term 'livelihoods' can be understood as the means of earning a living or accessing a source of income. In terms of poverty reduction strategies for the global south, livelihoods relates to a range of activities and services to promote self reliance, including formal and non-formal education, vocational training, waged employment, self employment, microfinance, agriculture programmes and social protection schemes.

Many international development programmes focus directly on these issues. However, very few manage to adequately address the rights and needs of disabled people, who account for one in five of the world's poor.

Disabled people in developing countries face a multitude of barriers to securing decent livelihoods. Globally, the International Labour Organisation estimates that some 386 million people of working age are people with impairments, with unemployment among disabled people as high as 80 per cent in many countries. This is primarily due to social discrimination and stigma, a pervasive negative view that disabled people are either unable to work, or cannot be accommodated in the workplace.

Much current work focuses on establishing disabled people in their own businesses. But not all disabled people need or want to be self-employed. Discrimination by employers against disabled people is massive and strong advocacy is needed to address the widespread prejudices.

Of those disabled people who do want to be self-employed, they must fulfil specific criteria set by microfinance services. Often community prejudice and discrimination prevent disabled people accessing capital. Advocacy with the private sector and microfinance institutions should be a key part of initiatives to promote the inclusion of disabled people in livelihoods work. A study in Uganda found that disabled entrepreneurs are an untapped market opportunity and that disabled people are often misinformed about microfinance institution terms and services and don't know how to gain these opportunities (Bwire, Musaka, Mersland 2009).

A further important issue is not to confuse the role of a Disabled People's Organisation (DPO) as a group advocating for their rights and an income-generating entity. Being both confuses the mandate of a DPO, and can lead to conflict of interest in leadership elections.

Much current work focuses on access to capital and financial services – yet this is only one element in the process of creating a successful business. Access to credit needs to be complemented with other services – such as skills development, access to technology, markets development, especially when working with people in socially marginalised groups including disabled people.

The documents below are grouped into key categories and have been produced in a partnership between Handicap International and Sightsavers. The full list can be found on:-

http://asksource.ids.ac.uk/cf/keylists/keylist2.cfm?topic=dis&search=QL_L10

SOCIAL ASSISTANCE

Social assistance and disability in developing countries
– Anna Marriott and Kate Gooding, Sightsavers International, July 2007

http://www.undp-povertycentre.org/publications/cct/Social_Assistance_Disability_Gooding_Marriott.pdf

ACCESS TO WAGED EMPLOYMENT

Assisting disabled persons in finding employment: a practical guide, Asian and Pacific Edition – 2nd ed
Robert Heron and Barbara Murray, International Labour Organisation, 2003

http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/documents/publication/wcms_bk_pb_92_en.pdf

Employability: a resource guide on disability for employers in Asia and the Pacific – Debra Perry, International Labour Organisation, 2007

http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/documents/publication/wcms_bk_pb_98_en.pdf

TECHNICAL AND VOCATIONAL TRAINING

Training for success: a guide for peer trainers – International Labour Organisation Regional Office for Asia and the Pacific, 2008

http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_132677.pdf

SELF-EMPLOYMENT AND ENTREPRENEURSHIP

Good practices for the economic inclusion of people with disabilities in developing countries: funding mechanisms for self-employment – Handicap International, 2006

<http://www.handicap-international.org/uploads/media/goodpractices-GB-2coul.PDF>

Count us in! How to make sure that women with disabilities can participate effectively in mainstream women's entrepreneurship development activities – Maureen Gilbert, International Labour Organisation, 2008

http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_106558.pdf

MICROFINANCE

Access to mainstream microfinance services for persons with disabilities: lessons learned from Uganda – Flavia Nakabuye Bwire, George Mukasa, Roy Mersland – New York, The Society of Disability Studies, Disability Studies Quarterly Vol 29, No 1 2009

<http://www.dsqsds.org/article/view/168>

MDG 2 – ACHIEVE UNIVERSAL PRIMARY EDUCATION

INCLUSIVE EDUCATION AND DISABLED CHILDREN¹

Philippa Lei and Ingrid Lewis

INTRODUCTION

Despite overall increases in school participation over the past decade, some groups of children continue to be left behind. Chief among these are disabled children. It is estimated that over one-third of all primary-aged children out of school are disabled children.² This amounts to approximately 25 million. In Africa alone, fewer than 10% of disabled children are in school. Other surveys suggest that disability has a greater impact on access to education than gender, household economic status or rural/urban divide.³

This is a fundamental human rights issue. The UN Convention on the Rights of the Child clearly expresses the right of each child to education (Article 28), and the responsibility of governments to ensure that disabled children receive quality education (Article 23). Additionally, the UN Convention on the Rights of Persons with Disabilities reinforces the rights of disabled people in relation to education and obligates governments to ensure an inclusive system (Article 24).⁴

Moreover, education for disabled children is essential for the alleviation of poverty and sustainable development. The impact of keeping disabled children at home and economically inactive, denying them education, as well as impacting family members who are unable to work due to caring responsibilities, all contribute significantly to the impoverishment of disabled people and their families.

WHAT IS INCLUSIVE EDUCATION?⁵

The UN Convention on the Rights of Persons with Disabilities recognises the right of disabled people to an inclusive education. But what does this mean and how does it differ from other approaches to education for disabled children?

Inclusive education aims to gradually change the whole education system, so that every school and every teacher is able to welcome any child (regardless of their disability, gender, poverty, ethnicity, etc.), and provide them with a good quality education alongside their peers. It is mostly about developing an attitude of flexibility and problem solving – enabling schools, teachers, parents and children to work together to solve the causes of exclusion.

Inclusive education theory says that children are excluded because of problems with the education system. For instance, exclusion happens because the school environment is inaccessible, or because teachers have negative attitudes or have not been well trained, or because the curriculum is not flexible to the needs of certain children. So the solution is to change the way the mainstream education system works, so that it can accommodate all sorts of different children. Figure 1 shows how inclusive education perceives 'the system as the problem'.

Integrated education focuses on getting children from marginalised groups (e.g. disabled children) into mainstream schools. It is often seen as a stepping stone to inclusive education, and is often implemented as part of a community-based rehabilitation (CBR) initiative. Integrated education often involves the provision of specialist equipment, assistive aids, etc.

Unlike inclusive education, integrated education tends to believe that it is the child's condition that causes their exclusion. For instance, exclusion happens because the child has mobility problems, or does not respond well to the lessons, etc. So the solution is to

try to change or cure the child so that he/she can fit into the existing education system. But the education system itself does not change. As such integrated education may help individual children to attend school at a particular point in time, but it may not lead to far-reaching changes in the education system that can make it easier for other excluded children to get an education in the future. Often integrated education works well at helping disabled children to be present in a classroom, but it may not always work towards ensuring their genuine participation in all aspects of school life, or their achievement in education.

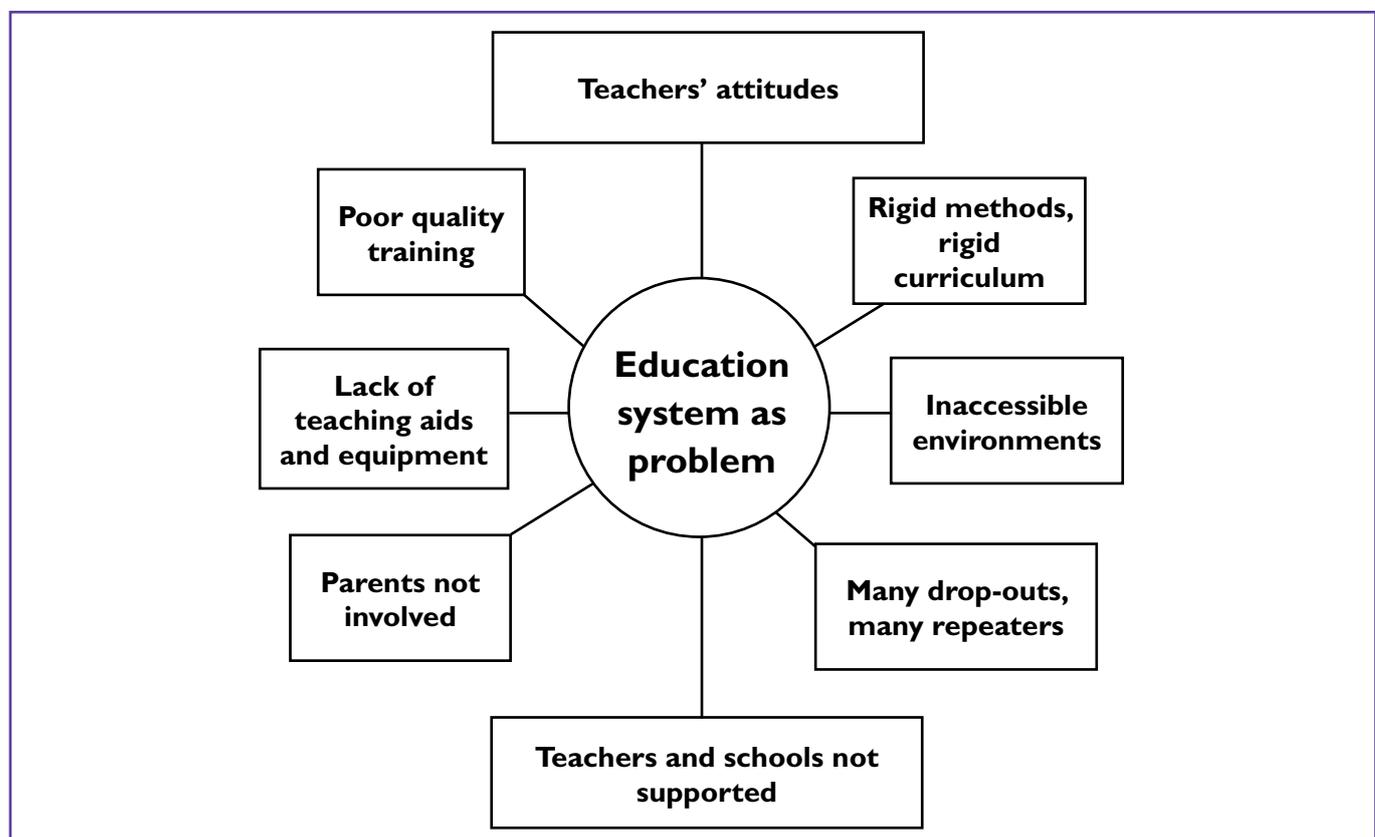


Figure 1: Inclusive education

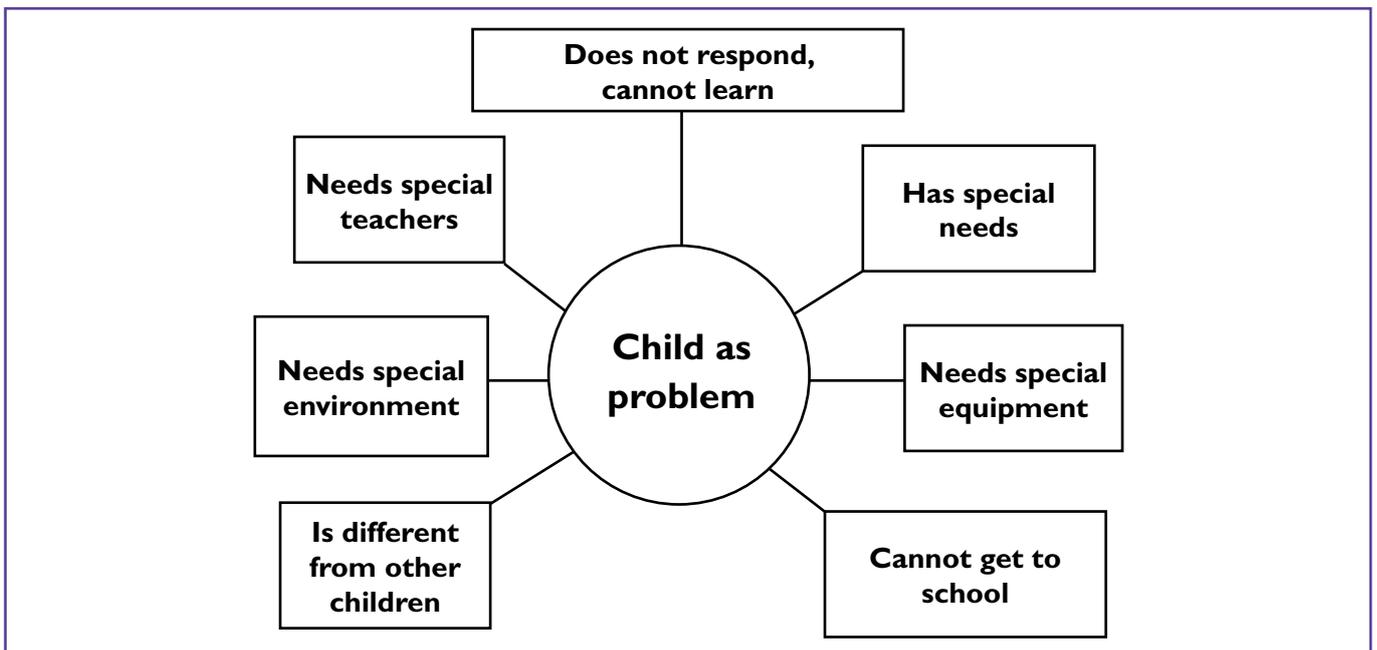


Figure 2: Integrated education

Figure 2 shows how integrated education is built around the concept of 'the child is the problem'.

It is important to mention that there is often not a totally clear-cut boundary between inclusive and integrated education approaches.

Special education creates separate education systems for different types of children (e.g. special schools for disabled children). Special schools may offer disabled children a chance to receive an education. But often they also risk violating other important child rights (e.g. residential special schools may violate a child's right to stay with his/her family and to grow up with his/her peers; or they may be places where the right to freedom from abuse is violated).

INCLUSIVE EDUCATION IS QUALITY EDUCATION

Though the focus here is particularly on inclusion of disabled children in education, inclusive education strategies improve learning for all children – a key issue given the pressing need to focus on education quality. Many programmes have shown these benefits. For example, in South East Europe teachers have collaborated on ways to support disabled children and produce their individual work plans, and this has promoted active, child-centred learning across their classes. In the Middle East and North Africa teachers have used tools such as the Index for Inclusion to improve school culture, infrastructure and teaching methods and so ensure that all children are welcomed and supported. In Lesotho, teachers who adopted

inclusive approaches said this helped them improve school for all learners and made them 'better teachers'.

HOW CAN EDUCATION BE MADE MORE INCLUSIVE?

Inclusive education is an aspirational process (it is something we always keep working towards, because we can always keep improving). It is not a quick-fix – the development of inclusive education takes time and requires everyone involved to commit themselves to permanent, ongoing action. A number of steps that can be taken towards making education more inclusive are as follows:

- 1. Determine who should be held accountable for ensuring that all children can fulfill their right to an inclusive education** – Parents, communities and governments all act as duty-bearers for this right and should be challenged on social prejudices that assume that children with learning, speech, physical, cognitive, or sensory impairments are unable to participate in mainstream education.
- 2. Promote positive attitudes towards difference** – Disabled children are often excluded from education as a result of society's lack of knowledge and negative attitudes towards them. Government, education officials, teachers, communities, parents, peers and NGOs need to understand disability as a social phenomenon whereby individuals with an impairment are socially excluded because of discriminatory attitudes rather than an inability to participate.
- 3. Support the process of changing the education system to one that is inclusive** – Currently the vast majority of education systems are not geared

to treating children as having diverse needs. For education systems to be able to provide quality education for all children, they need to be planned and resourced from the perspective of inclusion, particularly in terms of teacher recruitment, training and development and creating an environment supportive of inclusion (through, for example, materials and other supports in accessible formats – such as Braille or large font, building accessibility, inclusive curriculum, smaller class sizes). This planning and resourcing must be done in consultation with children, families and communities.

- 4. Promote child-centred teaching** – Teachers often think they need 'special skills' to teach disabled children. However, experience shows that, in the majority of cases, good, clear, accessible and participatory teaching skills are effective in including disabled children in learning, as well as improving education for all children. Training in child-centred teaching strategies can give teachers the skills and confidence to teach a diverse range of abilities and promote active learning to meet individual student needs.
- 5. Ensure that everyone is involved in working towards inclusion** – A 'whole community' approach must be taken if education is to become more inclusive. As such, active participation of children, parents, teachers, community members and leaders in making education more inclusive must be encouraged and strengthened.
- 6. Ensure multi-sectoral collaboration** – Disabled children and their families may receive services from a number of different sectors (e.g. social services or health services). For an inclusive education strategy to be effective it must be developed and supported in collaboration with these sectors. Close

collaboration with services for early childhood is particularly important because if impairments or developmental delays can be caught at an early stage, interventions can be made which will have an enormous impact on a child's inclusion.

There are also a number of useful resources that can support efforts to make education more inclusive.

WEBSITES

The Enabling Education Network (EENET) – www.eenet.org.uk – an information-sharing network on the issue of inclusive education.

Source – www.asksource.info – a collection of over 25,000 information resources on international health and disability.

REPORTS

P. Grimes' (2009) report *A Quality Education For All: A History of the Lao PDR Inclusive Education Project 1993-2009*, documents some of the challenges faced and lessons learned by Save the Children Norway over the course of its Inclusive Education Project in Lao PDR.

See: www.right-to-education.org/sites/r2e.gn.apc.org/files/A%20Quality%20Education%20For%20All%20Lao%20PDR.pdf

Save the Children UK's (2008) report *Making Schools Inclusive: How change can happen. Save the Children's experience* presents programme examples of inclusive education from 13 countries around the world.

See: www.eenet.org.uk/downloads/Making%20schools%20inclusive%20SCUK.pdf

The Stubbs, S./Atlas Alliance (2008) publication *Inclusive Education: Where there are few resources (revised)*, aims to provide a background and critical overview of key issues, concepts and strategies in relation to inclusive education, that are relevant to situations where economic resources and access to information is limited.

See: www.eenet.org.uk/theory_practice/IE%20few%20resources%202008.pdf

World Vision UK's (2007) publication *Education's Missing Millions* provides a number of recommendations as to how inclusive education can be best supported by governments through national education sector plans (ESPs) as well as by the donor community. It also considers some local and NGO initiatives to support inclusive education.

See: http://www.worldvision.org.uk/upload/pdf/Education%27s_Missing_Millions_-_Main_Report.pdf

UNESCO's (2009) Policy Brief on Early Childhood entitled *Inclusion of Children with Disabilities: The Early Childhood Imperative*, argues that early childhood care and education (ECCE) is a powerful means of nurturing diverse abilities and overcoming disadvantages and inequalities, and discusses main approaches to responding to developmental needs of young children with disabilities.

See: <http://unesdoc.unesco.org/images/0018/001831/183156E.pdf> (English)

<http://unesdoc.unesco.org/images/0018/001831/183156F.pdf> (French)

<http://unesdoc.unesco.org/images/0018/001831/183156S.pdf> (Spanish)

TOOLKITS/GUIDELINES

T. Booth and M. Ainscow's (2002) *Index for Inclusion: Developing learning and participation in schools*, is a set of materials to help schools reduce barriers to learning and participation for all children and young people. It also helps schools develop themselves in a way that values all students equally. It is available in over 20 languages.

See: www.eenet.org.uk/index_inclusion/index_inclusion.shtml

Save the Children's (2002) publication *Schools for All: Including disabled children in education*, provides guidelines to developing inclusive education practices for education staff.

See: www.eenet.org.uk/bibliog/scuk/schools_for_all.shtml

UNESCO's (2004) *Embracing Diversity: Toolkit for Creating Inclusive, Learning-Friendly Environments*, contains an introductory booklet and nine booklets, each of which contains tools and activities for self-study to start creating an inclusive, learning-friendly environment (ILFE).

See: www2.unescobkk.org/elib/publications/032revised/index.htm

The Inter-Agency Network for Education in Emergencies (2009) guide *Education in Emergencies: Including Everyone*, outlines useful principles for an inclusive education approach to education in emergencies and provides advice for planning, implementing and monitoring inclusive education in emergency contexts.

See: http://www.ineesite.org/uploads/documents/store/INEE_pocket_guide_Final.pdf

¹ This article draws on various briefing papers produced by WVUK and colleagues in other agencies, including Save the Children UK, Sightsavers International, Handicap International and the Enabling Education Network (EENET), as well as World Vision UK's report *Education's Missing Millions* and the 2007 review of World Vision Armenia's Inclusive Education Programme, undertaken by Ingrid Lewis of the Enabling Education Network.

² UNESCO (2006) *Education for All Global Monitoring Report 2007*.

³ Filmer, D. (2005) *Disability, Poverty and Schooling in Developing Countries: Results from 11 Household Surveys*. World Bank Discussion Paper.

⁴ Article 24 of the Convention states: "States Parties recognize the right of persons with disabilities to education." With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive, education system at all levels, and life-long learning, directed to:

- a. The full development of the human potential and sense of dignity and self worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c. Enabling persons with disabilities to participate effectively in a free society.

⁵ This section is taken from the 2007 review of World Vision Armenia's Inclusive Education Programme, undertaken by Ingrid Lewis of the Enabling Education Network (EENET).

MDG 3 – PROMOTE GENDER EQUALITY AND EMPOWER WOMEN

FREEDOM FOR THE PERSON: GENDER AND DISABILITY

Lorraine Wapling

DEFINITION

Gender: refers to socially and culturally determined relationships between men and women. These include the different attributes, status, roles, responsibilities, opportunities and privileges accorded to women and men as well as their access to and control of resources and benefits.

INTRODUCTION

Pressures on disabled people are being intensified by gender. For women it can lead to increased isolation, low self-esteem and negative feelings (DAA, 1997).¹ For men it can lead to lower self-esteem as they appear unable to meet the expectations of provider, and protector:

These experiences have consequences in terms of education, employment, personal relationships, victimisation and abuse – that in turn reinforce the general images.

Despite the focus on gender and development, disabled people are still being left out of the debate. That's probably because for so long the non-disabled community has simply failed to acknowledge their sexuality. Disabled people are often regarded as asexual people whose lives are so different to the norm, they're not affected by mainstream issues.

DIFFERENT EXPERIENCES FOR DISABLED WOMEN AND MEN

Gendered studies of disability (Gerschick, 2000)² reveal the following patterns:

- poverty hits women and girls harder due to patriarchal property ownership structures;
- aid is less likely to reach women and girls who are less able to compete in situations of scarcity;
- disabled girls and women are more vulnerable to domestic violence;
- disabled girls are likely to find their access to education more limited than girls in general and even disabled boys;
- women and girls disabled by war have few resources to survive;
- disabled women and girls who are sexually abused are likely to have few if any social supports;
- more women than men are classified as disabled, particularly as ageing populations mean larger proportions of the elderly are disabled women;
- disabled women are more likely to be living on their own, or in their parental family than men;
- disabled women are more likely to be divorced and less likely to marry than disabled men;

- disabled women and girls are more likely to experience sexual violence in relationships and in institutions.

DISABLED WOMEN

It is often considered that disabled women and girls experience double marginalisation on account of their gender and impairment. In patriarchal societies, the social role of women and girls is often primarily defined through motherhood and homemaking. With few opportunities to fulfill those ideals, disabled women will experience more discrimination than non-disabled peers. With decreased access to social, political, health and economic opportunities, they are highly vulnerable to poverty – and also are at greater risk of sexual and physical abuse.

Unfortunately, there is as yet little robust data available on the life experience of disabled women and girls. But from evidence produced by a growing number of disabled women's organisations, it's possible to see how their status as women makes it much harder for them to work their way out of poverty. Disabled women are far less likely to be able to own land or inherit property – and any children they have will be highly vulnerable as a result. Disabled women are often single parents, too. If they become disabled through

childbirth – as a result of lack of access to health facilities – it is common for husbands to divorce them. Similarly, if a woman gives birth to a disabled child, she is more likely to be left alone.

Despite the growing evidence of levels of marginalisation experienced by disabled women and girls, few mainstream women's initiatives routinely include them. The women's movement needs to be more aware of the needs of disabled women – and for mainstream programmes to be more inclusive.

FURTHER INFORMATION

Center for Reproductive Rights: *Reproductive violence*
http://reproductiverights.org/sites/default/files/documents/pub_bp_disabilities.pdf

Practical Action: *Women with disabilities – cooking, fires and smoke. A case study from Pakistan*
<http://www.practicalaction.org.uk/energy/boiling-point/docs/energy/docs44/bp46rahm.pdf>

WHO/UNFPA Guidance Note: *Promoting sexual and reproductive health for persons with disabilities* Nora Groce et al, Geneva, World Health Organisation, 2009
<http://www.who.int/reproductivehealth/publications/general/9789241598682/en/index.html>

¹ DAA (1997) *Resource Kit No 6*, London

² Gerschick, T.J. (2000) *Towards a theory of disability and gender*. In *Signs* 25(4): pp. 1263 - 1269.

MDG 4 and 5 – REDUCE CHILD MORTALITY AND IMPROVE MATERNAL HEALTH

POWER TO THE FAMILY: AN INTRODUCTION TO COMMUNITY-BASED REHABILITATION

Lorraine Wapling

INTRODUCTION

A disabled person's family is their key resource. That lies at the heart of Community-Based Rehabilitation (CBR). Traditionally, CBR has formed a major part of interventions aimed at disabled people – and there are a number of different ways to approach it.

BACKGROUND TO CBR

Governments and Non-Governmental Organisations (NGOs) have both been major providers of social service programmes as part of national development efforts. However, these have been planned and implemented using a top-down approach with either superficial or no participation from communities. Since the early 1990s there has been a gradual shift towards recognising the need to involve stakeholders in all talks on planning, implementation and evaluation. This rights-based approach is concerned with empowering communities to find ways to reduce poverty in locally appropriate and sustainable ways.

However, reliance on the top-down approach has been particularly pervasive for the disabled community – and in many cases continues today. That is because of strongly held assumptions by governments and the NGO sector that disabled people will always be dependent – rather than economically active – and need to be cared for. This individual model approach

has prevented disabled people from benefiting from most mainstream poverty alleviation programmes. With the advent of a growing Disability Movement, disabled people have started to challenge this approach and to begin demanding that they, too, are involved in decision making about issues affecting their lives. As Disabled Peoples' International explained, *'Nothing about us without us!'*

For over two decades now, the trend in rehabilitation has been moving towards placing greater reliance on family and community resources. Most disabled people in Africa – about 85% – live in rural or marginal urban communities and therefore have been unable or unwilling to go to the few rehabilitation and vocational training institutions that exist. Therefore, most disabled people were getting little or no support. The need for a more effective and accessible approach became obvious. So a method called Community-Based Rehabilitation was developed which saw families, carers and local communities taking a more important role.

WHAT IS CBR?

Commonly, Community-Based Rehabilitation (CBR) is defined as:

A strategy within community development for the rehabilitation, equalisation of opportunities, and social integration of all disabled people.

Currently in practice in more than 90 countries, CBR is a strategy for involving disabled people in the development of their communities by enabling them to adapt and participate. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and appropriate health, education, vocational and social services (WHO, 1994).¹

At the community level, CBR is a component of an integrated development programme. It should be based on members' decisions and will rely as much as possible on local resources. The family of the disabled person is regarded as the most important resource. Its skills and knowledge are promoted through training and supervision and, if needed, by encouraging the use of locally produced adaptive technology. The community is encouraged to support families to carry out rehabilitation at home and to open up all local opportunities for education, training and employment.

CBR IN PRACTICE

CBR is often practised as an outreach or extension service. The objective is to bring professional rehabilitation services to a larger number of disabled children and adults, particularly in rural areas. Once identified, the child or adult with impairment is subject to a regular programme of visits made to the community, often by a multi-sector team.

Despite the important desire to make this an empowering and community-based process, many CBR programmes are confined to working at family level and do not integrate or involve the wider community. In reality, many parents and families still feel isolated and are not getting enough support. Disabled

people are still largely excluded from mainstream community decision-making activities and continue to be subject to discrimination as CBR tends to reinforce the individual model (especially the medical model) approach.

NEW DIRECTIONS IN CBR

In recognition of the fact traditional CBR approaches have failed to really tackle disabled people's exclusion, major new guidelines have been developed by the World Health Organisation on CBR. These will include information on inclusive education, self-advocacy, community participation, empowerment, people-centred development, humanism, access and social change.

Many programmes now recognise the importance of DPOs (Disabled People's Organisations) and CBOs to ownership and sustainability – and are working to support their development. Capacity building of DPOs and parents associations means working with them to enhance their resource mobilisation and management capacities to prioritise, plan, implement and finance activities which bring benefits to members. These are strategic issues that require long-term support, as these organisations are usually fragile with low self-esteem and lack wider community recognition.

INVOLVING DISABLED PEOPLE

For any CBR programme to be sustainable, disabled people's involvement should be central. The empowerment of disabled women and other particularly vulnerable groups – such as people with learning impairments – should form priority agendas. An autonomous CBR programme does not exclude

professionals. However, the professional's role should not be seen only as that of 'transferring technology' but should begin also with recognising the clients' rights, power and ability. Disabled people, parents and the community also have knowledge and skills to share.

FURTHER RESOURCES

World Health Organisation – new CBR Guidelines 2010

www.who.int/disabilities/cbr

The Lancet Volume 374 No. 9704 pp. 1793 – 1866
28th November 2009 edition of the *Lancet* focused on disability and health issues, with articles by some leading experts in this field

www.thelancet.com

Policy into Practice and Practice into Policy: how disability practice informs policy: Uganda and Ghana – Diane Mulligan, Sightsavers International, UK, 2009

http://www.sightsavers.org/learn_more/reports_and_research/10817_09%20Diane%20Muligan%20Paper%20NDR%202009%5B1%5D.pdf

World Health Organisation paper on the links to CBR with different Millennium Development Goals, 2009

<http://www.who.int/disabilities/media/events/idpinfo031209/en/>

Disabled Village Children – David Werner, 2009 (updated)

http://www.hesperian.org/mm5/merchant.mvc?Store_Code=HB&Screen=PROD&Product_Code=B040

¹ WHO, ILO et al joint position paper (2004) *A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities.*

MDG 6 – COMBAT HIV AND AIDS

DISABILITY, HIV AND AIDS

Lorraine Wapling

INTRODUCTION

Excluding disabled people from HIV and AIDS programmes will jeopardise their overall success rates. So it's vital to be equipped and informed about this issue.

HIV and AIDS is a global pandemic that has attracted a lot of attention and resources over the past few years. It is recognised as being one of the most important factors in determining the long-term success of development and has led to a significant increase in levels of poverty in many developing countries. Here is some helpful information on how the HIV pandemic affects disabled people.

CURRENT SITUATION

HIV and AIDS is an almost wholly unrecognised problem among disabled people worldwide. That's despite the fact that disabled adults and children are at increased risk of sexual abuse, violence and rape (up to three times more likely according to the 2004 World Bank HIV and Disability study).

The physical development of infrastructures, life in institutions, sexual networks within some disabled communities and lack of access to legal rights make disabled people particularly vulnerable to abuse and infection. It's only recently that disability and HIV and AIDS has gained recognition as a subject which needs serious research and attention.

DISCRIMINATION

For many years disabled people have been excluded from work on HIV and AIDS because of wrongly held assumptions that they're not sexually active, don't use drugs and are at a lower risk of physical abuse (Groce, 2004).¹

In fact, evidence is emerging from around the world that disabled people are at increased risk for all HIV risk factors. For example, a study on reproductive Health and HIV and AIDS among disabled people carried out for the Disabled Women's Network in Uganda (DWNRO) in 2003, suggested disabled people – and disabled girls and women in particular – are likely to have more sexual partners than their non-disabled peers (25% males, 19% females had multiple partners). They're also more likely to practise unsafe sex (50% males, 43% females) putting them at high risk from HIV and AIDS infection. This same study also found that disabled people are highly vulnerable to sexual abuse and rape: 16% of women with disabilities cited their first sexual encounter as having been forced (DWNRO 2003).

Factors such as increased physical/sensory vulnerability, need for attendant care, life in institutions and the widely held customs of refusing to accept disabled people as reliable witnesses makes them easy targets for predators (Groce, 2004). Some 41% of the women in the DWNRO study reported their last pregnancy had been unwanted.

There are also some worrying cultural practices and beliefs emerging from countries like Tanzania and Malawi where it's understood that having sex with a disabled woman can cure HIV. More prevalent still is a belief that disabled people won't be HIV positive because they're sexually inactive. So young disabled women in particular are being deliberately targeted in increasing numbers.

HIGH RISK

Some surveys suggest disabled people – especially deaf and physically disabled women – can be at higher risk of substance abuse than their non-disabled peers. Yet they're less likely to have access to interventions or support (Groce, 2004). It's estimated that 30% of all street children have some type of disability, but this particular group of young people miss out on most of the general safe sex campaigns. There are very few sex education programmes designed for disabled people. With school attendance and literacy rates so low, disabled people are rarely exposed to information on HIV and AIDS.

Awareness of HIV and AIDS and knowledge on prevention is particularly low among deaf, blind and intellectually disabled adults and children. A DFID scoping study in Malawi (2009)² found a low awareness among deaf people of HIV and AIDS – with many believing they were two completely separate diseases. While not entirely inaccurate, the lack of understanding of a link between HIV and AIDS means many who are HIV-positive don't realise they could be at risk of dying or passing it on to others.

Disabled women often lack access to reproductive healthcare services and have very low awareness of mother-to-child HIV transmission. Only 60% of disabled women in Uganda made use of local antenatal care which makes it more likely they'll pass on the disease to their new babies. In addition, social and economic factors make disabled women some of the most difficult to reach groups for general HIV messages, reducing their ability to negotiate for safer sex.

SUPPORT SERVICES

The situation for disabled people who contract HIV is generally poor because most have little knowledge about how to access care and support services. There are also growing numbers of reports about how negatively people are treated when they try to seek that help. A study in Zambia (Smith et al 2004)³ said disabled women were reluctant to make use of reproductive health services because of the attitudes expressed by staff.

There is urgent need for more research on the uptake of anti-retro viral treatments among disabled people. There is a high possibility many are dying unnecessarily for lack of treatment. But disabled people who are HIV-positive also face many additional problems – even if they're aware of the treatments available.

Disabled people often need extra resources to travel to health centres because of physical limitations. Once there, the centre may be inaccessible to mobility impaired people. Medical staff are rarely able to communicate in Sign Language. So consultations may

be meaningless to deaf people – or worse still the deaf person may be reliant on a friend or relative to relay information which could be altered in a bid to hide the truth. Understanding the need for a well balanced diet, regularly checking general health and maintaining medical treatments could be difficult for those with learning disabilities without careful explanation. For busy medical staff without proper skills, this is unlikely to be given.

THE FUTURE FOR HIV AND AIDS

Major interventions around HIV and AIDS prevention, care, support, and mitigation are badly needed to ensure the message is getting through to disabled people. They need to be able to learn about HIV, how to protect themselves and how to cope if diagnosed. Services for those who are HIV-positive need to be made accessible and information should be available in a variety of formats to allow for the maximum number of disabled people to be able to learn about the disease for themselves. Training disabled people as peer educators and counsellors would significantly improve the reach of HIV programmes especially to the deaf community and should be considered as part of overall responses. The AIDS pandemic cannot be successfully mitigated unless disabled people are routinely included in all HIV and AIDS outreach efforts.

FURTHER INFORMATION

Health Canada – *HIV/AIDS and Disability: Final Report of the 4th International Policy Dialogue*

http://data.unaids.org/pub/Report/2009/20091111_hiv_and_disability_en.pdf

The Lancet Volume 374 No. 9704 pp. 1793 – 1866
28th November 2009 edition

www.thelancet.com

¹ Groce, Nora (2004) *Global survey on HIV/AIDS and disability*, World Bank/Yale.

² Wapling, Lorraine (2009) *Disability Issues in Malawi*, DFID scoping study.

³ Smith et al (2004) *Barriers to accessing safe motherhood and reproductive health services*, a study in Zambia, *Disability and Rehabilitation* 26 pp.121–127.

MDG 7 – ENSURE ENVIRONMENTAL SUSTAINABILITY

WHY SHOULD THE WATER AND SANITATION SECTOR CONSIDER DISABLED PEOPLE?

Hazel Jones

DISABILITY IS A POVERTY ISSUE

As many as one in five of the poorest of the poor is likely to be disabled. Poverty both causes and is caused by disability.

So why are poor people more likely to be disabled?

- Poor nutrition, bad water, poor hygiene and sanitation, limited health services, lack of information and HIV and AIDS are some of the causes of impairment.

And why are disabled people more likely to be poor?

- Inadequate treatment and equipment, lack of education or employment and discrimination all contribute to poverty. Disabled people are at high risk of HIV infection, as they have least access to information and tools to protect themselves.

HEADLINE FACTS

- Disabled people are among the poorest, most vulnerable and marginalised groups in society.
- Development targets for water and sanitation will never be equitably met unless disabled people's needs are included.

- The biggest problems for disabled people are obstacles in the environment, not their own impairment.
- Water and sanitation providers have a key role in reducing physical and infrastructural barriers in the environment.
- Disabled people often need only minor changes to be made to enable them to be included in ordinary water and sanitation service provision. Specialist skills and knowledge are therefore not required.
- Making water and sanitation facilities more accessible benefits everyone in the community, such as the elderly, the young and those who are ill.

THE IMPACT OF DISABILITY

The impact of disability is usually felt by the whole family, through lost income, treatment costs and the reduced well-being of everyone.

Lack of clean water and sanitation keep people poor, unhealthy and unable to improve their livelihoods. Disabled people have the least access to these services, which compounds their isolation, poor health and poverty.

A lack of accessible sanitation facilities can have a double impact. For example, in communities where women defecate at night, moving around in the dark is extra hazardous for a disabled woman.

Some disabled people manage with inaccessible facilities, others do not. Some receive support from disability services, such as individual equipment and advice. Others develop their own solutions, adapting local materials to make equipment that suits them.

A 60 year old disabled man had a simple toilet of bamboo pieces placed over a ditch. It was very old and did not provide any privacy so he only used the toilet at night. Finally the bamboo broke one night and he was found dead the next morning, having fallen into the ditch full of stinking, dirty refuse. CRP, Bangladesh

However, water and sanitation are personal issues, so solutions are often not shared with others, leaving disabled people and their families searching for solutions alone.

It is therefore clear that development targets such as the Millennium Development Goals of poverty reduction, improved health and access to safe water, will never be equitably met unless disabled people are included. Providers recognise the need to target the poorest sections of society, to provide more equitable access to basic services. This must therefore include disabled people.

BARRIERS AND OBSTACLES FACED

Most problems for disabled people in accessing water and sanitation facilities are caused not by their impairment, but by external factors, as in the examples below:

External factor	Example
Natural environment	Muddy pond/river banks Distant water sources
Physical infrastructure	Narrow entrances and steps High well walls
Institutional	Strategies ignoring disabled people Lack of consultation with disabled people Lack of knowledge and information
Social	Prejudice and isolation

It is often possible to make changes in this external environment. This is where the knowledge and skills of the water and sanitation service provider are indispensable.

WHY ADDRESS THE ISSUE OF DISABILITY

Human rights

The right to safe water is enshrined in Article 25 of the UN Declaration of Human Rights and in Article 27 of the UN Convention on the Rights of the Child.

For the majority of disabled people in low-income communities, accessing their basic needs and rights is a daily struggle.

Benefits of inclusive facilities

Many people, such as the elderly, pregnant women, girls, parents with small children and people who are injured or sick may have difficulty with balance, coordination, weak grip, squatting or lifting. Because of this they experience many of the same problems as disabled people, although they are not described in this way. Inclusive planning of water and sanitation services therefore benefits the whole community, and often involves only minor adjustments to ordinary services.

Cost effectiveness

It is much cheaper to plan from the outset to make services inclusive for disabled people, than to provide 'special' services which only a small minority benefit from.

Gender

Where traditional family ties are strong, support is offered to disabled and frail family members. Improved services for disabled people also benefit those who provide that support, usually women and girls (by reducing their workload), who would otherwise be taken out of school.

Before the treadle pump was installed, it used to take Mrs Nourn a whole morning to fetch four buckets of water from the river. As she is blind, one of her children would guide her there and back. Now she can draw water without a guide and all her children can attend school.

INCLUSION AND ACCESS IN PRACTICE

Although the water and sanitation sector is developing planning and design approaches to understand and respond to the needs of different communities, still the service delivery process often excludes disabled people, and their concerns and needs remain hidden.

The nature of exclusion

Exclusion of disabled people often arises through a lack of awareness or thought. For example, holding a meeting on the second floor of a building, with no lift or ramp, excludes people who have difficulty walking. Social factors can also lead to exclusion, such as when it is the norm for powerless groups, such as women, disabled people and people of low caste, to speak only when asked a direct question, thereby limiting participation. This is why inclusive design has to be seen to benefit the whole community, by making buildings and services accessible for everyone.

What does equal access mean?

Disabled people do not expect more or better facilities than other people, only equal access and opportunity to participate in family and community life. However, equal access and equality of opportunity do not mean that everyone must be treated exactly the same, as some people may need something different or extra. For example, for a person with difficulty walking to have equal access to water (i.e. to spend a similar amount of time fetching water as her neighbour), the water point needs to be nearer to her home than to that of her neighbour. Services need to be designed to be able to provide a flexible range of options to accommodate a range of needs. Some

disabled people have healthcare needs, and require certain equipment to support them to access water and sanitation facilities – a wheelchair for example. However, to provide this individual support, but without accessible services being available, is often of little or no use to the disabled person concerned.

But I'm not a disability specialist...

The needs of most disabled people could be met by ordinary facilities and services. Service providers only need a little more information, thought and awareness to make the differences to ensure the inclusion of a disabled person. Usually a 'special' service is not required. This means that service providers cannot simply pass responsibility for disabled people to 'specialists'. Doing nothing is unacceptable. All service providers need to consider ways to ensure that disabled people are not excluded from their services and programmes.

Collaboration with disabled people

Whilst engineers have design knowledge and skills, they are not always aware of the needs of disabled people. Disabled people on the other hand, do understand what their access needs are, but because they are not generally knowledgeable about engineering, they tend to be unaware of what solutions may be possible. So, when planners and engineers start the process of designing a water and sanitation project, they should consult local disabled people's organisations, including women's sections, to get their input.

FINAL THOUGHTS

Water and sanitation services cannot ignore the issue of disability for much longer. The knowledge and skills

of the water and sanitation sector will play a vital part in making changes in the physical environment and in service delivery approaches, to provide more inclusive access to disabled people and other vulnerable groups.

This briefing note raises awareness about the need to address disability issues within water and sanitation service provision.

KEY REFERENCES

Jones, H.E. and Reed, R.A. (2005) *Water and sanitation for disabled people and other vulnerable groups: designing services to improve accessibility*. Water Engineering and Development Centre; DFID: UK.

<http://wedc.lboro.ac.uk/wsdp>

DFID (2000) *Disability, Poverty and Development. Issues Paper*. Department for International Development: UK.

<http://www.dfid.gov.uk/Pubs/files/disability.pdf>

Elwan, A. (1999) *Poverty and Disability: a survey of the literature*. World Bank: Washington.

<http://siteresources.worldbank.org/INTPOVERTY/Resources/WDR/Background/elwan.pdf>

European Disability Forum (2002) *Development Cooperation and Disability*. European Disability Forum: Brussels.

<http://www.edf-feph.org>

A full report by Hazel Jones of WEDC including details of all the material used is available at

www.Lboro.ac.uk/well

MDG 8 – DEVELOP A GLOBAL PARTNERSHIP FOR DEVELOPMENT

TASKS FOR THE WORLD – THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES – A BRIEF GUIDE

A better deal for disabled people across the globe – that is the aim of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Ratified by 83 countries – including the UK – the document came into force in May 2008. Although the Convention does not set out any new rights for disabled people, it has helped identify how existing rights treaties apply in a disability context.

It's more of an implementation document – setting out how existing rights should be put into practice for the benefit of disabled people. It is also far more detailed than any other existing treaties.

'The Convention is intended as a human rights instrument with an explicit, social development dimension,' says UNESCO, *'it is both a human rights treaty and a development tool'* (Mainstreaming disability in the development agenda, UNESCO 2008).

Overall, it provides a framework for policy analysis and implementation. It is also a tool for Disabled People's Organisations (DPOs) and Non-Governmental Organisations (NGOs) in advocating for disabled people's rights.

All countries that have ratified will need to make sure their domestic legislation meets the international

standards set out in the Convention. In many developing countries that may well involve the adoption of disability and anti-discrimination policies for the first time.

The UNCRPD also breaks new ground by being the first international rights treaty to explicitly include articles on international co-operation. There are now clear obligations for international aid programmes to adopt principles of equality and non-discrimination – and for ensuring all interventions are accessible to disabled people.

Accessibility now needs to be considered by all programmes. This may well involve the development of new strategies to ensure disability is mainstreamed throughout programmes and projects – and that disability-specific work is carried out to redress some of the systemic disadvantage experienced by disabled people.

The UN Convention says ratifying countries should:

- **carry out policies, laws and administrative measures to secure the rights recognised in the Convention** and abolish regulations, customs and practices that constitute discrimination (article 4);

- **recognise that all persons are equal before the law**, to prohibit discrimination on the basis of disability and guarantee equal legal protection (article 5);
- **combat stereotypes and prejudices** and promote awareness of the capabilities of disabled people (article 8);
- **guarantee that disabled people enjoy their inherent right to life** on an equal basis with others (article 10), ensure the equal rights and advancement of disabled women and girls (article 6) and protect disabled children (article 7);
- **identify and eliminate obstacles and barriers** and ensure disabled people can access their environment, transportation, public facilities and services, and information and communications technologies (article 9);
- **ensure the protection and safety of disabled people** in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters (article 11);
- **ensure the equal right to own and inherit property**, control financial affairs and have equal access to bank loans, credit and mortgages (article 12). They are to ensure access to justice on an equal basis with others (article 13), and make sure disabled people enjoy the right to liberty and security and are not deprived of their liberty unlawfully or arbitrarily (article 14);
- **protect the physical and mental integrity of disabled people**, just as for everyone else (article 17), guarantee freedom from torture and from cruel, inhuman or degrading treatment or punishment, and prohibit medical or scientific experiments without the consent of the person concerned (article 15);
- **guarantee freedom from exploitation, violence and abuse**. In case of abuse, states shall promote the recovery, rehabilitation and reintegration of the victim and investigate the abuse (article 16);
- **allow disabled people to live independently**, be included in the community, choose where and with whom to live and have access to in-home, residential and community support services (article 19). Personal mobility and independence are to be fostered by facilitating affordable personal mobility, training in mobility skills and access to mobility aids, devices, assistive technologies and live assistance (article 20);
- **ensure that disabled children have equal rights**, shall not be separated from their parents against their will, except when the authorities determine that this is in the child's best interests, and in no case shall be separated from their parents on the basis of a disability of either the child or the parents (article 23);
- **promote access to information** by providing information intended for the general public in accessible formats and technologies, by facilitating the use of Braille, sign language and other forms of communication and by encouraging the media and Internet providers to make online information available in accessible formats (article 21);
- **ensure disabled people are not subjected to arbitrary or illegal interference with their privacy**, family, home, correspondence or communication. The privacy of their personal, health and rehabilitation information is to be protected like that of others (article 22);

- **eliminate discrimination relating to marriage, family and personal relations.** Disabled people shall have the equal opportunity to experience parenthood, to marry and to found a family, to decide on the number and spacing of children, to have access to reproductive and family planning education and means, and to enjoy equal rights and responsibilities regarding guardianship, wardship, trusteeship and adoption of children (article 23);
- **ensure equal access to primary and secondary education, vocational training, adult education and lifelong learning.** Pupils with support needs are to receive support measures, and pupils who are blind, deaf and deaf-blind are to receive their education in the most appropriate modes of communication from teachers who are fluent in sign language and Braille. Education of disabled people must foster their participation in society, their sense of dignity and self worth and the development of their personality, abilities and creativity (article 24);
- **ensure disabled people have the right to the highest attainable standard of health without discrimination on the basis of disability.** They are to receive the same range, quality and standard of free or affordable health services as provided for other persons, receive those health services needed because of their disabilities, and not to be discriminated against in the provision of health insurance (article 25);
- **enable disabled people to attain maximum independence and ability,** by providing comprehensive habilitation and rehabilitation services in the areas of health, employment and education (article 26);
- **remember disabled people have equal rights to work and gain a living,** and prohibit discrimination in job-related matters, promote self-employment, entrepreneurship and starting one's own business, employ disabled people in the public sector, promote their employment in the private sector, and ensure they are provided with reasonable accommodation at work (article 27);
- **recognise the right to an adequate standard of living and social protection;** this includes public housing, services and assistance for disability-related needs, as well as assistance with disability-related expenses in case of poverty (article 28);
- ensure equal participation in political and public life, including the right to vote, to stand for elections and to hold office (article 29);
- **promote participation in cultural life, recreation, leisure and sport** by ensuring provision of television programmes, films, theatre and cultural material in accessible formats, by making theatres, museums, cinemas and libraries accessible, and by guaranteeing disabled people have the opportunity to develop and utilise their creative potential not only for their own benefit, but also for the enrichment of society. Countries are to ensure their participation in mainstream and disability-specific sports (article 30);
- **provide assistance to developing countries as they put the Convention into practice, ensuring international co-operation is inclusive of and accessible to disabled people;** and facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices (article 32);
- **ensure implementation and monitoring of the Convention,** by designating a focal point in the government and creating a national mechanism to promote and monitor implementation (article 33).

A Committee on the Rights of Persons with Disabilities, made up of independent experts, will receive periodic reports from States parties on progress made in implementing the Convention (articles 34 to 39).

An 18-article Optional Protocol on Communications allows individuals and groups to petition that Committee once all national recourse procedures have been exhausted.

For more information on the UNCRPD and a full text version of the treaty, go to UN Enable website at [**www.un.org/disabilities**](http://www.un.org/disabilities)

Guidelines and practical issues

EXTRACTS FROM ‘WORLD VISION INTERNATIONAL DISABILITY DEFINITIONS AND POSITION PAPER’

World Vision International Disability Working Group, co-ordinated by Hitomi Honda, World Vision Global Centre Disability Adviser

This position paper aims to bring World Vision colleagues an understanding on disability issues in order to prepare the organisation towards mainstreaming and inclusion of disabled children and adults. Without the inclusion of disabled children and adults in our work, ‘Our Vision for Every Child, Life in All Its fullness, Our prayer for Every Heart, the Will to Make It So’ cannot be fulfilled.

INTRODUCTION

In 2004, World Vision’s Triennial Council Resolution recognised disability as a cross-cutting issue and recommended that we ‘integrate disability awareness into existing policies’. World Vision has been supporting children in especially difficult circumstances including disabled children for a long time. Then why has the WVI Board of Directors recommended taking action on disability now?

Supporting disabled children and adults has been regarded by many World Vision offices as additional and extra work: ‘We will help them if we can find a donor for a special project or if we have extra funds’, as if we have an option. Disabled people have not consistently been participants and beneficiaries of World Vision’s regular programmes and projects in the

same way that non-disabled people have. This may be so because disabled people are often considered as an issue or category that comes under medicine/health, rather than simply as people who should benefit from and participate in all World Vision programme areas. However, awareness on disability issues and on the need for mainstreaming has been strongly supported by World Vision UK and this issue has been receiving more attention across the Partnership in recent years. There are more and more World Vision colleagues who see the need to mainstream disability issues in World Vision policies and include disabled people into our programmes/projects. But do we have a clear, unified understanding on what we mean by ‘disability’? Is it about people who have impairments? Is it about impairments or a health condition? Or is it ‘functional limitation’ caused by impairment or discrimination? Is it about maltreatment and injustices faced by people who have impairments? What are the issues World Vision needs to tackle in our work as a Christian, humanitarian and development agency? Unless World Vision as an organisation has the same, clear understanding on what disability is and what the challenges are, World Vision will not be able to fulfill the recommendations of the 2004 Council Resolution and achieve inclusion of all children in our work.

CONSULTATIONS WITH WORLD VISION COLLEAGUES

Towards the end of 2005, World Vision's Transformational Development (TD) Disability Working Group (DWG) recognised the need for World Vision to have a unified understanding on what disability is and an approach that is suitable to support disabled people in our work of transformational development. Recognising that to support disabled people with provision of therapies, assistive devices or special education is not enough for the mainstreaming and inclusion of disabled people or to challenge inequality and injustices disabled people face in their everyday life and in society, the social model of disability was introduced within World Vision. We hope that this understanding on disability issues helped us recognise that disabled people are faced not only with their physiological impairments but also social exclusion, discrimination and abuse.

We hope that this will help us see the need for mainstreaming disability in policies and strategies, and including disabled people in our regular programmes and projects. Our target becomes clearer when we separate impairments that people have, from the exclusion and discrimination that are placed upon people who have impairments. With this recognition, definitions and models of disability as you will see below were introduced to World Vision colleagues earlier this year:

PROPOSED DEFINITIONS:

Impairments are problems in body function or structure. Examples would include lacking part of or all of a limb; having a limb/organ/mechanism of the body that does not fully function effectively and/or efficiently.

Impairments include physical, sensory, neurological, intellectual, mental, or any physiological long or short term impairment.

Disability is a result of the limitations imposed on people with impairments by attitudinal, institutional, and environmental barriers to their participation in society.

Mainstreaming disability issues and inclusion of disabled people:

As the experience of the Women in Development (WID) work teaches us, mere inclusion and recognition of disabled people's value are not enough. For disabled people to be included in our regular programmes and projects, capacity building and empowering of disabled people alone are not enough. As with the social model of disability, society and non-disabled people must also be targeted by our work so that mainstreaming of disability issues will be addressed and disabled people will be included in our programmes and projects on equal terms with non-disabled people. Just as women's voices and experiences need to be included in any decision-making, policy or strategy, disability equality will not be achieved without the participation of disabled people.

Goal of disability mainstreaming: To have disabled adults and children included in all our programmes and projects as equal participants and beneficiaries just as non-disabled adults and children are.

Definition of disability mainstreaming:

Mainstreaming is a 'strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic, and

societal spheres so that disabled people benefit equally and inequality is not perpetuated' (modified from the ECOSOC's gender mainstreaming definition).¹

Mainstreaming includes disability-specific activities and affirmative action, whenever disabled people or non-disabled people are in a particularly disadvantageous position. Disability-specific interventions can target disabled people exclusively, non-disabled and disabled people together, or only non-disabled people, to enable them to participate in and benefit equally from development efforts. These are necessary temporary measures designed to combat the direct and indirect consequences of past discrimination.

Mainstreaming is not about adding a 'disabled people or disability component' or even a 'disability equality component' into an existing activity. It goes beyond increasing disabled people's participation; it means bringing the experience, knowledge, and interests of disabled people and non-disabled people to bear on the development agenda.

It may entail identifying the need for changes in that agenda. It may require changes in goals, strategies, and actions so that both disabled people and non-disabled people can influence, participate in, and benefit from development processes. Mainstreaming disability is about the transformation of unequal social and institutional structures into equal and just structures for both disabled people and non-disabled people.

FREQUENTLY ASKED QUESTIONS

Q: Why do we need to define disability?

A: There are a number of definitions and understanding on what disability is. By having a unified understanding and separating two different issues

(health/impairment and discrimination/exclusion in society), World Vision will be able to refocus and be more effective in including disabled people in its programmes and projects.

Q: Does the social model of disability deny medical intervention?

A: No, it does not deny the need for medical intervention or support for some people with impairment. The social model is a deliberate attempt to shift our focus away from the health, body and ability or inability of individuals and to move towards a focus on the barriers and discriminations that exist in the society. This is because so much attention has been focused on individuals' impairments/body but not on the inequality of human rights and opportunities. As the European Forum of Disability clearly points out, *'Preventing impairments through vaccinations, eliminating diseases that cause impairment and improving birth practices does nothing to improve the human rights of disabled persons already living'*.

Q: Why is the social model of disability relevant to World Vision's work?

A: In our effort to mainstream disability, it is essential that all possible barriers and difficult areas for disabled people are recognised. Impairment or health conditions are areas that have been getting a lot of attention and support. However barriers of social exclusion and discrimination disabled people face have been largely overlooked in the past when almost all people with perceived impairments experience such barriers.

The process of Transformational Development *'helps people and their communities recognise the resources that lie within themselves to make change possible'*.

While some disabled people need support in medical intervention, all disabled people need to and have the right to participate in society as non-disabled people do. All the areas that World Vision supports such as health care, agriculture production, water and sanitation, education, micro-enterprise development, disaster mitigation and relief and emergency relief are important to disabled people's lives although these are also the areas that they have often been excluded from. Including disabled people in these areas in the same way non-disabled people are included will help ensure disabled people's participation as equal citizens of society. The social model of disability helps us explicitly recognise these barrier areas and the need to support disabled people in these areas rather than focusing our work on medicine and health.

Q: Is medical intervention/support different from the medical model of disability?

A: Absolutely. Some people seem to be confused about the two and think they are the same. While impairments and the need for medical support for some people with impairments must be acknowledged, the medical model is the view that holds disabled people accountable for the discrimination and social exclusion they face. Under the social model, society is accountable for these obstacles placed on disabled people.

Q: How about empowerment and capacity building of disabled people?

A: These are important in supporting disabled people, and the social model does not rule them out. The model however emphasises the society's disabling barriers and discriminations, as these have been the

most neglected areas. We can see an example from the Women in Development (WID) approach too. While empowering and providing medical support to some disabled people is important in disabled people's access to equal opportunities and rights, social barriers and discrimination must be addressed and dealt with separately, which is the area that has been neglected and ignored in past. In other words, much attention has been paid to individuals' ability/inability and capacity, but not enough on the injustices and inequality that exist in our society. And this is the very reason why impairments and 'disability' (as in social barriers) need to be addressed separately.

Q: But doesn't 'disability' come under health?

A: We must remember to separate issues from people. We should also remember that body or physiological health is not everything for a person as a whole. Some aspects of us as human beings come under health, but many other aspects don't.

In our conventional term, what does 'disability' mean? Are we talking about issues or people? If it is about issues, are we talking about health issues or discrimination, social exclusion and abuse against disabled people?

Impairments and impairment related issues (or disability in the sense of health) come under health and medicine. We must remember to separate disability or impairment related issues from people who have impairment. The issue of disability is recognised by World Vision as a cross-cutting theme. It is a cross-cutting issue that comes under every sector of our work (agriculture, WATSAN, MED/MFI,

education, health, employment/vocational training, environment, child protection, disaster mitigation, emergency and relief, etc.).

Q: How about prevention of impairment?

A: World Vision has many colleagues who have health and medical backgrounds. There are other agencies that World Vision can work with such as national and local level government agencies, local and international non-governmental organisations, and UN bodies. Their expertise is fundamental to our programming in prevention of impairment. However we must remember that this should come under our health programme/projects.

¹ ECOSOC, 1997 cited in Carol Miller and Bill Albert, March 2005
Mainstreaming disability in development: lessons from gender mainstreaming

EXTRACTS FROM ‘WORLD VISION INTERNATIONAL – GUIDELINES ADDRESSING DISABILITY’

World Vision International Disability Team

So, God created man in his own image,
In the Image of God he created him;
Male and female he created them.
God saw all that he had made, and it
was very good.

(Genesis 1: 27, 31)

The human person, the living being, beyond all exterior appearances, reflects Love who created him with the ability to love and be loved, with his being, his faculties and his freedom. Every person has in his/her constitution the honour, glory and dignity of God. Man is the being with whom God speaks intimately in the ‘*garden in the evening*’ (Gen 3:8) he is the reality which God created for himself, in order to pour into it the fullness of his own life, to be in communion with this reality, which he has given the ability and responsibility of love for others and of communion with others in freedom.ⁱ

WHY DO WE NEED TO THINK ABOUT WORDS WE USE AROUND DISABILITY?

The power of words and images to reflect and shape community perceptions of people with a disability is widely acknowledged. Language is a powerful tool which can be used to change stereotypes and attitudes.ⁱⁱ

Language both reflects and shapes our understanding of reality and can also influence the thoughts and actions of those around us. When using language to refer to persons with disabilities, if one speaks as if there is a problem with a person who has an impairment, they will probably take a different approach in their treatment of the person than if they recognise that any problems related to a person’s impairment may be problems stemming from the attitudes, systems or practices that create disabling barriers.

Negative disability language also impacts children. Language shapes the way children think of themselves and others. Negative language can adversely affect a child’s emotional development, and can become a barrier to building a healthy sense of self-esteem.

It is important to re-examine the language we commonly use and evaluate the meanings and connotations of our words, including their origins in relation to persons with disabilities. These guidelines for addressing disability do not dictate which terms should or should not be used. Rather, these guidelines are intended to help raise consciousness amongst World Vision staff and the partners we work with about the language we use and issues surrounding ‘Disability’.ⁱⁱⁱ

Most people want to be respectful of others yet may not realise how the language they use disempowers others.

We “inherit” language and often do not give it much thought, yet we do have a choice and we can make conscious choices to use words and terms that say what we mean and give power, dignity and respect to all people.

There are a number of guidelines on disability terminology developed by other organisations. Most share the basic principles of respecting dignity, rights and diversity of persons with disabilities, and ask speakers not to label. Websites of some of the guidelines are available at the end of the paper.



THREE WORDS AROUND “DISABILITY”

Before we look at different terminologies, think about how you may be using the word “disability”

Impairments include physical, sensory, neurological, intellectual, mental or any physiological long or short-term condition.^{iv} Examples would include lacking part of or all of a limb; or having a limb/organ/mechanism of the body that does not function fully, effectively and/or efficiently.

Function/functional limitation: While impairments may affect functioning of your body organs, it may not necessarily affect your ability to perform or function in certain activities.

Disability is a result of the limitations imposed on persons who have impairments by attitudinal, institutional, or environmental barriers to their participation in society.^v

World Vision International separates ‘disability’ (social issue) from ‘impairment’ (medical or individual issue) in order to clearly see each of the two issues a person may be facing. To separate the two issues also enables us to take specific actions and approaches towards focused solutions.

Let us also be aware that a person who has impairment may not necessarily have **functional limitation** but often faces disabling barriers or discrimination. Because of discrimination or assumption by others, the person’s rights may be violated and therefore the person may not be able to participate in school, community activities, meetings, leisure, or employment, to marry, or to have children.

Although we need to separate the three issues, rather than being so caught up with the use of words “impairment”, “disability”, and “functional limitation”, it is more important to be aware that everyone has different abilities and inabilities, many have impairments, and everyone is special.



GUIDELINES WHEN ADDRESSING A DISABLED PERSON:

- 1 Uphold dignity and respect.** We want to put the person first, and not label the person with her or his physiological condition (e.g. mobility impairment or learning difficulty), the cause (e.g. polio or Down's syndrome), or assistive devices the person uses (e.g. wheelchair or eye glasses).
- 2 Do not assume on behalf of the person.** For example, one cannot know if someone who lost a leg due to traffic accident is currently suffering or feeling challenged. Perhaps the accident happened thirty years ago, and the person might not be suffering from the trauma any longer. It is inappropriate to assume and address the person as sufferer or as being challenged.
- 3 Victimising vocabularies are disempowering.** A person who was just injured by a landmine may be considered a victim. But it is an insult to continue regarding the person as victim because she/he might have overcome the emotional trauma, disabling discrimination, or her or his mobility difficulty, and have regained confidence and independence.

4 Do not generalise and assume that persons with disabilities are 'unhealthy' or in need of medical support (e.g. surgery or therapy). A person who has difficulty walking or seeing may be perfectly healthy. Conversely, addressing non-disabled persons as 'healthy' or 'able bodied' could be inappropriate and inaccurate. Many non-disabled people do have health problems.

5 Consider what is normal to you may not be normal to others, because of our personal, cultural or other differences or backgrounds. People may fall into the category of majority or average, but everyone is normal and abnormal in one way or the other.

6 The word "defect" is unfortunately sometimes used in referring to a person in some parts of the world. A machine can have a defect but a person cannot be defective because we are all made in the image of God. In the same manner, **no one is incomplete or complete, while everyone is complete and incomplete.** We are fearfully and wonderfully made.

7 Acknowledge all persons have the same basic needs as well as different needs. All persons have different abilities and inabilities. For example, someone who uses eyeglasses would not want to be referred as "eyeglasses", "someone with special needs" or "differently abled". To address someone as a "person with special needs" would put the person in a separate category and therefore could discriminate or isolate her or him from the mainstream population. In the same way, everyone is special and gifted, and has different abilities and inabilities. **Do not label a person with "special needs or gifts", or "differently able".**

WEBSITES FOR DISABILITY TERMINOLOGY

Clark, L. and Marsh, S. (2002) *Patriarchy in the UK: The Language of Disability*.

<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>

Disability Awareness in Action Definitions of Disability – a Briefing Paper

www.daa.org.uk

The Disability Rag The Problem with Challenge

<http://www.raggededgemagazine.com/archive/challenge.htm>

Disability Services Queensland, Queensland Government (2006) *A way with words: Guidelines for the portrayal of people with a disability*

http://www.disability.qld.gov.au/community/communication/way-words/documents/way_with_words.pdf

European Disability Forum Adopt a disability attitude
<http://www.1million4disability.eu/adopt.asp?langue=EN>

Kids Together, Inc. People First Language: A commentary by Kathie Snow

<http://www.kidstogether.org>

Mobility International USA Respectful Disability Language

<http://www.miusa.org/ncde/tipsheets/respect/>

United Spinal Association *Disability Etiquette: Tips on Interacting with People with Disabilities*

<http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>

World Health Organisation Disability and Rehabilitation Team (June 2001) *Rethinking Care from the Perspective of Disabled People*

<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>

- i Committee for the Jubilee Day of the Community with Persons with Disabilities The Person with Disabilities: The Image of God and a Place of His Wonders. http://www.vatican.va/jubilee_2000/jubilevents/jub_disabled_20001203_scheda1_en.htm
- ii Community Disability Alliance, Queensland Government (1995) *A Way with Words: Guidelines for the Portrayal of People with a Disability*.
- iii Clark, L. and Marsh, S. (2002) *Patriarchy in the UK: The Language of Disability*, <http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/language.pdf>
- iv World Vision International Disability Working Group (2006) *Disability Position Paper*.
- v World Vision International Disability Working Group (2006) *Disability Position Paper*.
- vi Illustration from Werner, D. (1999) *Disabled Village Children*. <http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.htm>

EXTRACTS FROM ‘WORLD VISION INTERNATIONAL DISABILITY WORKING GROUP POSITION PAPER ON WHEELCHAIR DISTRIBUTION’

International Disability Working Group

RATIONALE:

To many people who do not have a physical means of mobility, wheelchairs can provide opportunities not only to get around but also to be independent and to access education and employment opportunities. Wheelchairs can contribute to improving quality of life for those who need them. Motivation, a UK based Disabled People’s Organisation, estimates a number of people requiring wheelchairs in developing countries at twenty million, and says: ‘Donated wheelchairs may seem like the logical solution to the lack of wheelchairs in low-income countries.’ (Factsheet 1: Donated wheelchairs in low-income countries, Motivation – www.motivation.org.uk). Well, aren’t they?

There are many charity organisations of a good will who want to assist people who require wheelchairs in the majority world. Some of them have contacted World Vision and donated wheelchairs to be distributed in World Vision programme and project areas. There are a number of issues that need to be considered if and when World Vision is engaged in wheelchair distribution. These issues also apply to provision of other assistive devices such as eyeglasses, prosthetic limbs, orthotics, crutches, etc.

Four types of wheelchair provision (source: Motivation):

1. Donation of recycled wheelchairs from industrialised countries
2. Mass production and export of free wheelchairs to low-income countries
3. Local workshop. A wheelchair workshop may be a simple workshop that produces and repairs wheelchairs using locally available materials. A physiotherapist or other qualified therapist should conduct assessment and fitting based on individual requirements. A workshop may also produce crutches, canes, bars, walkers, special seats, standing frames, and other simple assistive devices.
4. Mass production/distribution of low-cost wheelchairs working with local organisations in low-income countries

When involved in wheelchair distribution in the past, World Vision used one of the first two methods: donation of recycled wheelchairs from industrialised countries, or mass production and export of free wheelchairs to low-income countries. However there are problems surrounding these methods:

1. Wheelchairs that do not meet individual body size and needs:

Very often wheelchairs are distributed without a specialist. It may be World Vision staff, a medical doctor, village health worker, community worker, or village leader who distribute chairs. Without an appropriate assessment and fitting done by a professional, sitting in a wheelchair many hours a day every day can be not only uncomfortable for the user but may cause health problems, deformity and even death.

2. Wheelchairs that do not meet the local terrain/environment:

Wheelchairs that are manufactured in economically developed countries are often not suitable for use in developing countries. Think of the road conditions for instance. Roads in most parts of developed countries are smoothly paved without holes, whereas roads in most parts of developing countries can be so muddy or filled with holes or gravel that you need a four-wheel drive vehicle. Or some people may live in a mountainous or sandy area where we will find roads that we find it difficult to call roads. If automobiles have problems going on such roads, surely people will have difficulty using wheelchairs in such an environment, particularly for those who have weak arms or who are without much strength. Not only that, wheelchairs that were made for developed countries can break very easily in the harsh environment of the majority world.

3. Problems when wheelchairs break:

Wheelchairs manufactured in developed countries are easily broken in developing countries. If the following measures are not taken into consideration, wheelchairs that are broken will just sit in the corner of the users' houses, taking up much space and collecting dust.

- Are there repair shops or people who can repair them in the area?
- Are spare parts available locally?
- Are users able to afford repair costs?

4. Maintenance and follow-up:

Very importantly, users need regular follow-up by specialist or trained personnel to see whether the chair fits the person and their needs, and if there are any problems with the chair. To be able to use wheelchairs in a harsh environment, the chairs need regular maintenance as well. Are these services available locally?

5. Undermining local wheelchair manufacture:

The following is a quote from *It's Not about Wheelchairs* published by Whirlwind Wheelchair

'If one of the goals of international aid organisations is to develop sustainable programs, that is, to help people to help themselves, then free imports of used wheelchairs from the US defeats that purpose in an important way – it undermines the development of local wheelchair manufacture. If any foreign company, in any other industry, sold its products below cost in another country, it would be accused of unfair competition and dumping, in violation of international trade agreements. Yet we applaud the free distribution of wheelchairs that cost a lot to refurbish, ship and distribute, even if these costs are hidden because they are paid for through donations, volunteer labor, and 100% subsidized shipping.'

6. Transportation of wheelchairs:

Transporting wheelchairs from one country to another is expensive and takes a lot of staff time. It takes a lot of time for the Support Office to arrange for shipment

and prepare paperwork, and for the National Office to receive them as they often have to go through bureaucratic custom procedures that sometimes, if not often, require 'fees' that do not come with the gift. Often wheelchairs and other supportive devices donated as free gifts do not come free, as there are other costs that they very often incur such as tax and bribe money.

WVI POSITION ON WHEELCHAIR DISTRIBUTION:

To support people who are in need of wheelchairs, the following recommendations are advised as viable means of sustainable development (recommendations below are in priority order):

1. If wheelchairs are produced locally, purchase them rather than import from the minority world/developed countries. Main advantages are:

- Wheelchairs more suitable to individual users and local terrain will be provided
- New wheelchairs can be purchased at relatively low costs
- Locally made wheelchairs are locally repairable.
***If your office will purchase local wheelchairs, ensure a professional/specialist runs a quality check of wheelchairs.

2. If wheelchairs are not produced locally, establish (or support establishing) a wheelchair workshop in cooperation with government, DPOs, and Wheelchair Specialist Organisations (for example Motivation and Whirlwind Wheelchair International).

Sustainability of the workshop and affordable price of wheelchairs will be key issues, but if successful, the work will benefit not only World Vision programme areas but also surrounding areas or even the entire country. The workshop can also produce simple, low-tech assistive devices.

3. If wheelchairs must be brought in from the minority world/developed countries, ensure to have:

- Assessment and fitting by specialist at the time of distribution
- Training to users and their family members on the use and maintenance of the wheelchair
- Follow-up/ongoing service of check-up for users, and of maintenance and repairing of chairs.

4. Ensure that assessment is done by professionals, not only on individual wheelchair users but also on the environment of the area where wheelchairs will be used:

- Conditions of local roads, terrain, housings and public buildings.

In 2008 the World Health Organisation published comprehensive guidelines on appropriate wheelchair provision, designed and endorsed through a consultation process with a wide range of groups in the sector. This is available as a free-to-download resource:

Guidelines on the provision of manual wheelchairs in less resourced settings
<http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/>

EXTRACTS FROM ‘PRACTICAL LESSONS FROM FOUR PROJECTS ON DISABILITY-INCLUSIVE DEVELOPMENT PROGRAMMING’

Sue Coe and Lorraine Wapling

This article looks at early lessons learnt from inclusion of disabled people, based on socially inclusive principles, in World Vision programming work in Angola, Armenia, Cambodia and Senegal. Externally-led reviews and evaluations conducted between July 2007 and April 2008 drew out 7 common key lessons. In summary: the substantial effect of stakeholders’ attitudinal issues on practical implementation; the importance of authentic consultation with a range of disabled people; appropriate budgeting considerations; and a need for caution regarding livelihoods work.

World Vision UK has had a DFID Programme Partnership Arrangement (PPA) since 2006 which includes an objective to mainstream disability in its work. This does not mean World Vision is increasing its disability specific projects, it means World Vision is actively trying to find ways to ensure all of its work brings benefits to disabled children and adults living in focus communities.

This practice note has been written to share World Vision’s experiences so far on introducing new approaches to including disabled children and adults, based on reviews and evaluations from early projects in four countries on three continents.

EXTERNALLY-LED REVIEWS ON DISABILITY INCLUSION WORK TO-DATE IN ARMENIA, ANGOLA, CAMBODIA AND SENEGAL - SEVEN KEY LESSONS EMERGED

In recent years, World Vision has started to examine what a socially inclusive view of disability means for its work. It is a mammoth change, and one which has no established precedent in programming work, either its own or those of other comparable international NGOs. One of the first tasks undertaken as part of World Vision/DFID’s PPA was to commission externally-led reviews and evaluations to honestly critique early initiatives in 4 countries:-

- **Armenia** – support inclusive education approaches in mainstream state primary schools and kindergartens, including advocacy work with the national education ministry.¹
- **Angola** – project to support and empower Disabled People’s Organisations (DPOs) to improve their integration into Angolan society using a rights-based framework.²
- **Cambodia** – work to include disabled people in three mainstream Area Development Programmes; plus review and alter practices/policies at the central offices of World Vision in Phnom Penh.³

- **Senegal** – project in the rural Kolda district to identify and address the barriers facing disabled people locally in order to increase access to mainstream services.⁴

The reviews and evaluations took place between November 2007 and April 2008. Even though these projects were different in nature and conducted in diverse geographical and cultural situations, **seven key lessons emerged** from them, briefly outlined below.

1. Challenging staff and community attitudes is THE key ‘first step’ to seeing positive change towards the inclusion of disabled people in development work – early effective training on social model principles is crucial

All four reviews resoundingly demonstrated the impact that staff and stakeholder attitudes had on project activities and progress towards effective inclusive practices. People’s perceptions of what disability represents (the model they use), cultural beliefs and practices (such as what causes impairments) and a deep-rooted fear of how to interact with disabled people all contribute to holding back progress on inclusion.

Project staff were largely unaware of the social model concepts – partly because effective training and clear direction were not provided early enough. This led to project staff continuing to view disabled people as a separate group in receipt of specialist support. Therefore there was little or no impact on how work was implemented and disabled people were still not routinely consulted as key stakeholders. A key recommendation from the Cambodia evaluation was that staff and communities in which they

worked needed to have a clearer understanding of the social model approach. In Armenia whilst there were improvements in general attitudes towards the inclusion of disabled children in mainstream classes it was still seen largely within the context of how medical interventions could be used to enable that to happen. In Angola, training on social model inclusion happened in the latter half of the project, so had limited impact as the foundations of work were well-established by then.

Cultural beliefs and practices often precluded people from understanding disability inclusion. For example, one review discovered a pregnant staff member refused to sit in the same room as a disabled colleague for fear the impairment would be passed on to her unborn child. Progress on inclusion cannot be made until underlying beliefs and prejudices are identified, openly acknowledged, explained and challenged.

It is still rare to find disabled people in full-time employment in developing countries so many staff had barely any professional contact with disabled people. Many non-disabled staff interviewed in all reviews spoke about the fear of doing or saying the wrong thing. In Armenia that fear led to reluctance by teachers and parents to move forward themselves on ideas for inclusive lessons before ‘professionals’ could be consulted. Overcoming that fear by focusing on ‘system level’ changes rather than on the child’s impairment has since produced very positive progress.

2. Old habits ‘die hard’ – there is a tendency to drift from socially inclusive principles back towards medical/charity model approaches when implementation starts unless vigilant

All projects had a tendency to 'drift' to medical/charity approaches, even if disability awareness training had happened. A number of key project staff continued fundamentally to view disability as a medical/charity issue and couldn't acknowledge work was drifting away from its socially-inclusive intentions. In one case this resulted in project money designated for empowering DPOs actually going to NGOs clearly still focusing on service delivery for disabled people.

A range of reasons were identified accounting for this tendency, with some variation between projects:

- Project staff didn't consciously adopt social model inclusive principles at the outset, therefore personal attitudes/practices more aligned with medical/charity model thinking prevailed;
- Staff were not equipped early enough through appropriate attitudinal training to adopt social model approaches;
- Much NGO work can naturally be medical/charity model in nature so socially inclusive approaches were new thinking to some staff.

3. Beware of the power of medical professionals!

Medical model thinking has long been predominant in work with disabled people. Medical intervention has an important place for disabled people – as it does for everyone – but often disabled people are subject to the views of medical professionals who hold great power and make assumptions about what is best for them. Disability inclusion work can easily become focused solely around outputs like rehabilitation even when there is explicit desire from disabled people not to do so.

For example, World Vision Armenia attempted to break with this assumption and integrate medical efforts within an inclusive education project to ensure children had access to medical interventions if they were deemed necessary. However in practice the medical professionals became the dominant force in a project which was originally designed as a tripartite relationship between specialists, teachers and parents.

'...there still appears to be a strong emphasis, however, on achieving improved social acceptance and integration through approaches that rehabilitate or "fix" the individual disabled child, rather than through approaches that comprehensively change the way society thinks and works so that it welcomes anyone who is "different". That is, attitude change appears to have been built around a medical rather than social model approach to disability.'
Armenia review

The teachers and parents deferred to the specialists which delayed progress as there were not enough specialists to cope with the demand. Rather than the teachers and parents working to find solutions to access issues they tended to wait for professional advice and assume that their adaptations would not be as good. In effect it disempowered parents and children.

4. Consultation with disabled people (rather than making assumptions) is critical; 'disabled people' are not a homogeneous group – consultation processes should reflect this

Many non-disabled people tend to think of disabled people in homogenous terms. Too often assumptions

are made in assessments and reviews about them, rather than undertaking authentic consultation processes involving disabled people.

Further, the label of 'disabled people' covers a broad range of impairment groups (physical, sensory, intellectual, psycho-social) and socio-economic status. As with any cross-section of society there are also gender, age, ethnic and a multitude of other power dynamics.

The projects reviewed tended to only receive inputs from a limited range and representation of disabled people – typically, urban-based men with physical impairments. For example, in Angola and Senegal too much emphasis was placed on a small selection of the most articulate and geographically close disabled people with the result that the impact of the projects was substantially minimised. In Senegal the review found an absence of any representation from people with psycho-social impairments and in Angola the lack of consultation with deaf people and those with learning impairments resulted in these groups being excluded from work.

Another general concern was the lack of participation by disabled women who are widely recognised as facing double discrimination of gender and disability. The Senegal review noted that:

'Disabled women suffer double marginalisation. They are rejected by men who refuse to get married with them and by their families-in-law who are against their marriage... As a result of these barriers, they remain single or widows, bringing up their children lonely and in extreme poverty.'

5. 'Practice what you preach' – disability inclusive environments are essential

Perhaps one of the most surprising results to emerge from the reviews was the lack of attention paid to ensuring that the project environments were as accessible as possible. We came across many instances where project delivery work was not accessible to many disabled adults or children. For example, the Armenia inclusive education project was being run from a national office that does not have a meeting room accessible to wheelchair users. In Senegal the reviewers held a stakeholder focus group discussion with disabled people where it quickly became apparent to them that no Sign Language interpretation was being provided for Deaf participants in the group, until the reviewers specifically requested it. In Angola no provisions were made for producing any of the project documentation and training materials in large font or Braille formats.

Projects which aim to empower disabled people and increase their inclusion in development work should pay particular attention to access issues. For example, if training is to be provided consideration needs to go into where this will take place (e.g. wheelchair access to venue and washrooms, local transport links), how the training will be delivered (e.g. disability awareness of trainers, alternative formats for printed materials, sign language interpretation, regular breaks/variation in activities in the schedule) and how the participants are selected and informed (e.g. over reliance on one or two DPO's can exclude many disabled people as noted above). Project briefings, meetings and monitoring visits should all be accessible – the best

way to ensure they are is to have a small focus group (or steering committee) made up of representatives from across the disability community (think not only about impairment but also gender, age, ethnicity etc.). Test out ideas on this group first before attempting to engage with the wider disability community.

6. Budget for inclusion – it need not cost much

One of the main findings from the evaluation of the Angola DPO empowerment project was that insufficient funds were allocated for access – for example to hire accessible venues, and paying for interpreters, advocates and personal assistants. This applied to the other projects too.

One of the most common reasons projects cite for not including disabled people is perceived heavy cost – this essentially stems from medical model thinking and is not true. For the majority of disabled people small adjustments to the way project activities are carried out is all that is needed to secure their involvement – for example informing participants in good time ahead of meetings, taking a bit of extra time at meetings to allow for more breaks, producing information in simplified language forms, checking for venue accessibility – these will not incur significant budget costs. However reprinting information in large font or Braille, hiring sign language interpreters or advocates (for those who are deaf-blind or have moderate/severe learning impairments), covering the costs of personal assistants and guides (for mobility and visually impaired people), helping parents cover the cost of childcare etc. will have budget implications and will need provision. The key issue is that these

should be included at **design** stage of the project, not once the project is underway when it is then regarded as 'additional' cost. Evaluations in Cambodia and Angola recommended in future funds should be specifically set aside for mainstreaming across the organisation so the necessary adjustments could be made.

7. Livelihoods work - include in mainstream programmes rather than establishing separate initiatives; analyse barriers and plan very carefully before starting

Three of the evaluations had livelihood components (in the case of Cambodia a 'sister' project specifically placing young disabled people into work placements). Without exception the projects significantly struggled with this component. It has proved a complex issue requiring more research, but indications from these evaluations generally showed progress would probably be best achieved through mainstream livelihoods programmes specifically examining the barriers to disabled people in being included in them. The main points emerging from the evaluations to highlight here are that this area if not handled well may lead to the increased exclusion of disabled people; and that doubling up DPOs as income-generating entities confuses the purpose of the DPO, and can cause serious long-term problems in the internal accountabilities of the DPO. As the Angola evaluation pointed out:

'The income generating components of this project led to confusion over the project intent and did nothing to ease the tensions, conflict and rivalry caused by competing over resources... It changes the nature of the organisation from being a focal point for lobbying to one providing services.'

CONCLUSION

Disabled people are often the most excluded and subject to the deepest poverty of any community group. By recognising the explicit need to include disabled people benefits will also be gained by a range of other 'hard to reach' socially excluded groups – for example children, older people, pregnant woman, ethnic minorities. By uncovering the mechanisms which exclude disabled people and applying these lessons above, mechanisms which are excluding many others in communities should also be found.

NOTES

1. Lewis, Ingrid (2007) *Review of World Vision Armenia's Inclusive Education Programme*
2. Wapling, Lorraine; Paxe, Nsimba; Parkinson, John (2008) *Empowerment of Disabled People's Organisations – World Vision Angola – Final Evaluation Report*
3. Vanthon, Srey; Viriya, Yit; Socheat, Cheng; Kim Lay, Ong; Sopho, Prak; Moth, Trok; Phally, Ith; Sarin, Sok (2007) *Report on the Evaluation of World Vision Cambodia's Disability Mainstreaming Project*
4. Sanon, Emilienne; Cumberland, Judi; Weston, Peter; Coe, Sue (2008) *Rapport de la Revue a Mi Parcours du Project de Promotion de L'Egalite de Chances pour les Personnes en Situation de Handicap dans la Region de Kolda au Senegal*

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COMMUNICATIONS CASE STUDIES GUIDELINES – DISABLED PEOPLE

Jane Betts and Esther Williams

1. The dignity and rights of every child and adult are to be respected in every circumstance.
2. Special attention is to be paid to each person's right to privacy and confidentiality, to have their opinions heard, to participate in decisions affecting them and to be protected from harm and retribution.
3. The best interests of each person are to be protected over any other consideration, including over advocacy issues or the promotion of rights.
4. World Vision needs strong stories to inform and provide impetus for our advocacy activities and as a child focused agency, case studies featuring children are most in demand. Always ask permission of the child to talk to them and find out more about their story, not just the adult/carer with them.
5. Reporting on disabled people should be consistent with social model principles i.e. focusing on the need for environmental, institutional and attitudinal change by society rather than the individual having to make adaptations in order to fit in.
6. Do not define disabled children and adults by their impairments. Consider carefully whether the person's impairment is crucial to the story. The reporter should present an accurate and balanced portrayal of disabled children, with reference to their social, cultural and economic environment, avoiding manipulation or sensationalisation of text and images. For example: *'Fatima is currently unable to attend school because the building is inaccessible with narrow doorways and no ramps for wheelchair passage'*, instead of *'Fatima has cerebral palsy and cannot attend school'*.
7. Do not use negative or figurative language, which may be open to interpretation, or make inaccurate generalisations. Avoid using degrading, victimising or shaming language and images. Use appropriate and specific terminology where needed. Refer to World Vision International 'Guidelines Addressing Disability'.
8. Allow the subject of the story to speak, or otherwise communicate, for themselves.
9. Avoid taking photographs out of context or intrusive close-ups.
10. Avoid using 'them and us' expressions as it divides disabled and non-disabled people. Simply use 'disabled and non-disabled people', 'people with and without disabilities' or 'people with and without impairments.'
11. Reporting on disabled children and adults should demonstrate their inclusion within a community setting and avoid consolidating negative stereotypes by setting them apart.

How do we get from here to there?

PRACTICAL GUIDELINES ON DISABILITY INCLUSIVE PROGRAMMING

Lorraine Wapling, Kevan Moll, Sue Coe

PREPARATION

- Ensure disabled people with different impairments can participate in community development by assessing environmental and attitudinal barriers.
- Engage with disabled people locally. Try to find out if there are any representative organisations of disabled people (DPOs). If unsure about whether your plans are accessible, ask DPO representatives for advice.
- Consider employing local disabled people in your programme. They're more likely to identify and encourage others to participate.
- Identify and support disability champions at all levels within national offices, sectoral, departmental, programme and project teams.

PROGRAMME

- Separate data on participants by disability as well as gender, to measure inclusion. Break this down further into common impairments to improve monitoring. The easiest way is to add a box stating disabled alongside male and female. This can be expanded on with type of impairment.

- Ensure questions on any issue (income level, coping strategies, school attendance, health status, HIV awareness, etc.) that are put to non-disabled people are also put to a minimum number of disabled people (at least 10% of total interviewees). This will build up a picture of whether the situation is the same or different for disabled and non-disabled people.
- Ensure inclusion of disabled people in any objective follows through into relevant indicators, outcomes, outputs, activities, budgets and evaluation. Insert additional columns in tables for disability checklists.

ACCESS

- Ensure a standard line for costs of disability access/ inclusion within all budgets as a fixed percentage (2-5%) of activities or overall costs to cover interpreters, guides, transport, production of material in alternative formats, adaptations to premises, etc. If this is labelled 'inclusive support costs', it will benefit many other vulnerable people (elderly, pregnant women, PLWHA). Make inclusion an integral part of the budget.

MONITORING

- Ask some key questions. Are disabled women, men, girls and boys specifically included in this programme/strategy/activity? How are they included? Is their participation measured on a regular basis and in periodic evaluations? Is their inclusion adequately resourced? Are there any barriers to their participation and if so, how can these be overcome?

WORKING

- Establish the numbers of disabled people in the area from the outset. If this isn't possible, use national disability statistics or the World Health Organisation (WHO) global figure of 10% as the minimum target. The percentage of disabled people in any programme or consultation should aim to at least match – and arguably exceed – the estimated percentage in the community.
- When carrying out mapping exercises of local community-based organisations, NGOs, INGOs, etc., ensure you ask questions about DPOs, self-

help groups of disabled people or others working on disability – so you get a good sense of existing activities and resources.

- Carry out resource mapping of disability services to establish links for referrals of support. Find out if there are community-based rehabilitation (CBR) programmes, as you may be asked for help in providing these. The emphasis is on helping people to access aids, appliances or services which can be the first step towards participation – this in itself is not inclusion.
- Include disabled people and disability issues in mainstream development while at the same time deploying targeted interventions to support and build capacity among disabled people and DPOs.
- Ensure diversity of disabled people (women, men, girls and boys with mobility, hearing, visual, intellectual and multiple impairments).
- Partner with DPOs to identify and engage disabled people, and address local issues. Consider ways of supporting their advocacy efforts.

Which way in?

HOW TO HOST ACCESSIBLE EVENTS

What a tragedy if people with disabilities couldn't get into a workshop designed just for them. But that does happen. Here's how to avoid such embarrassment.

It can seem difficult to plan for access – there are many things to consider. Having physically accessible venues may be difficult in an area where the choice is limited, but this is not the only factor to consider.

Overall, it's important to think about access issues ahead of time, so as much as possible can be done to make the event accessible.

It's best to set-up an access group with representatives from a variety of Disabled People's Organisations (DPOs) to help you to consider a wide range of perspectives. These discussions need to happen as early as possible – and make sure your budget can accommodate access provisions.

The following guidelines will help you start thinking about some of the key issues. These are designed with large events in mind – such as a conference or workshop. But they can also be adapted to cover any meeting:

EVENT PUBLICITY

1. Publicise your event in places familiar to disabled people such as through local DPOs. Make note of accessible features, and invite people to notify

organisers if they have a disability-related support that isn't listed.

2. Put 'sign-language interpreters available on request' in your advertisements. Make sure you budget for this provision and provide interpreters as needed.
3. Provide interpreters with papers, data etc. in advance so they are prepared.
4. Pay attention to contrast and type size in visual advertisements for people with low vision. Most large print documents should be produced with body text in 18 points type in Arial, or Times New Roman.
5. Some disabled people will require an assistant to attend with them (as a guide, personal assistant or advocate). It's important to take into account these assistants when estimating the number of participants.

EVENT TRANSPORT

1. Choose a venue centrally located and easy for people to reach through public or private transport.
2. For disabled participants, consider arranging transport for them – or through their local DPO to ensure they can get to the venue. Reimburse their taxi fare if public transport isn't an option.

3. Have someone stand by the main entrance to direct people to the meeting room, and provide support to those who request it.

EVENT PARTICIPATION

1. Make sure the event space is accessible. Check width of doors (at least 36 inches), accessible bathrooms, seating space in event room, wheelchair space, lighting, ambient noise and head-level obstructions.
2. Make sure staff and volunteers know what accessible features are available, their location and how to use them.
3. Ask all presenters and participants what accommodations or modifications they require ahead of time so changes can be made. For example, if a presenter is a wheelchair user, ensure any raised podiums are accessible.
4. Make sure there are no obstructions – such as chairs, tables – blocking major pathways.
5. Prepare alternative formats of materials. For example, provide handouts on CD in Word format. A few copies of the materials should be available in 16-point font for people with low vision.
6. If using sign language interpreters, make sure they're well positioned both to hear what the presenter is saying and to be seen by deaf people in the audience.
7. Ask presenters to read all the information presented in Power Point presentations – or other similar visual aids – to facilitate the participation of people who are visually impaired or are using a sign language interpreter.
8. Allow for individuals to take unscheduled breaks if needed. But also consider the need for regular short breaks (five minutes each hour) when planning the schedule.



World Vision

World Vision UK

World Vision House,
Opal Drive, Fox Milne,
Milton Keynes. MK15 0ZR
tel: +44 (0)1908 84 10 00
textphone: +44 (0)1908 24 45 44
fax: +44 (0)1908 84 10 01
email: info@worldvision.org.uk
www.worldvision.org.uk

This book is available for free
download at
www.worldvision.org/travellingtogether

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