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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 -

NO

ISBN number 978-0-9564162-1-6

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Financial support for this publication was provided by DFID under its Programme Partnership Arrangement with World Vision UK.

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.iddcconsortium.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 I 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 polices (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 underfive 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 rewritten 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).

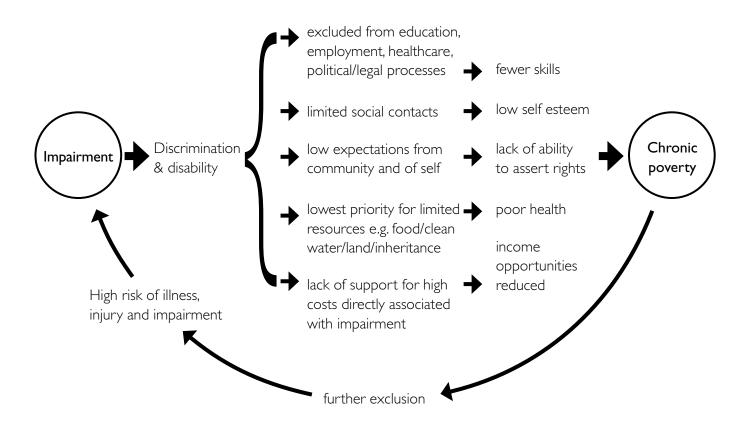
THE CYCLE OF DISABILITY AND CHRONIC POVERTY

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 incomegenerating 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_LI0

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 Organsation, 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_I32677.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.dsq-sds.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 I 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.

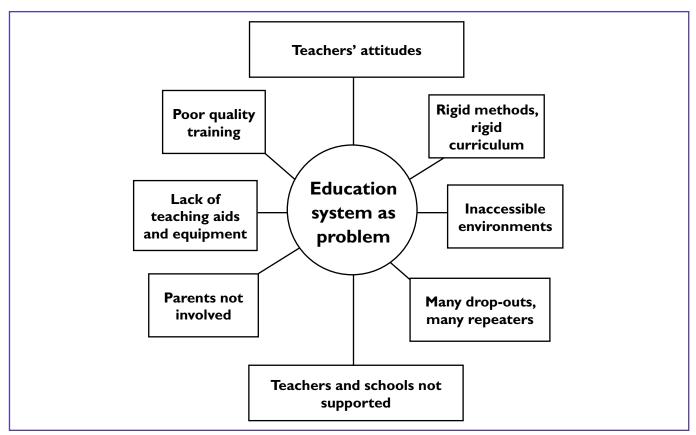


Figure 1: Inclusive education

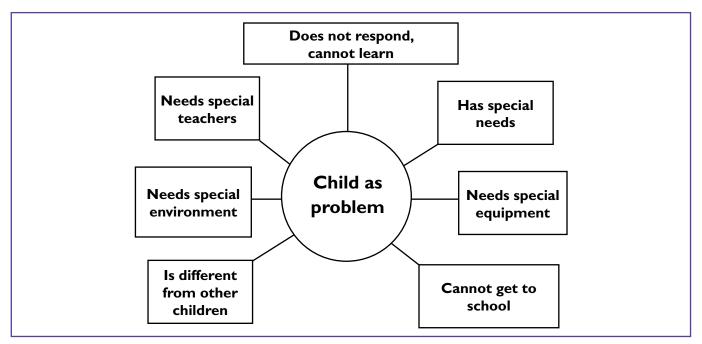


Figure 2: Integrated education

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:

- I. 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%20 schools%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%20 few%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

- 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.
- 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). 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

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).

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%20NNDR%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/

idpdinfo031209/en/

Disabled Village Children – David Werner, 2009 (updated)

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

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).

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 nondisabled 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

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

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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

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).

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.

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. 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:

- I 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.lmillion4disability.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_schedal_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):

- I. 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:

I. 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 fourwheel 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):

- 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.
- 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.

- 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.
- 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.

I. 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.

 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

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- Wapling, Lorraine; Paxe, Nsimba; Parkinson, John (2008) Empowerment of Disabled People's Organisations – World Vision Angola – Final Evaluation Report
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This paper is from an article published in Development In Practice: Volume 20, Number 7, September 2010, pp 879-886. Development in Practice is available online at: http://www.informaworld.com/DIP

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.
- 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.'
- II. 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

 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

- I. 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

- 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 I 6-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.