Disability, Equality, and Human Rights

Oxfam GB

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ADD

Action on Disability and Development (ADD) has a vision of a world where all disabled people are able to participate as fully as they choose, at every level of society. To achieve this, it works in partnership with networks of disabled people in some of the poorest communities in the world, to help them to campaign for the rightful inclusion of disabled adults and children in society.

ADD is the only British-based agency supporting self-help development work, exclusively, with groups of disabled people in Africa and Asia. Since 1985 it has supported more than 75,000 disabled people in their self-help activities and their fight for basic rights and equal opportunities.

ADD's aim is to see democratic, representative, and active networks of disabled people who are campaigning for the rights of all their members, whatever their disability. Through facilitating the growth of these organisations, locally and nationally, ADD aims to help to promote a vibrant people's movement.

For more information about the work of ADD, visit www.add.org.uk

Disability, Equality, and Human Rights

A Training Manual
for Development and Humanitarian Organisations

Alison Harris with Sue Enfield

Oxfam

Action on Disability
and Development

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Foreword

For too long disabled people – most particularly disabled women and children – have been marginalised and excluded from mainstream society. There is no country in the world which can confidently claim that its disabled citizens have realised equal rights and equal opportunities. Rarely are disabled people equally able to exercise the vote, attend school or college, gain employment, use public transport, and live independently – the basic rights that most non-disabled people take for granted.

The United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities, adopted by the UN General Assembly in 1993, imply a strong political commitment by member states to take measures to ensure that disabled people can realise equal rights. However, implementation of these measures is patchy – despite the fact that many international agencies acknowledge the links between disability and poverty.

International development organisations and policy makers have yet to adopt and implement policies which are fully inclusive and which affirm the value of social diversity. While it is acknowledged that disabled people are among the poorest members of their communities, many agencies consider their needs to be related solely to their impairments (in line with 'the medical model of disability'), rather than considering their needs in the context of their rights as equal members of society ('the social model').

In the United Kingdom, legislation now requires public services, facilities, and buildings to be accessible to disabled people. Disability-rights activists campaigned for years for changes in legislation to outlaw discrimination and to gain recognition. But the fundamental principle that society needs to change if disabled people are to realise their full potential has yet to be internalised fully by development and humanitarian agencies, although policies to this effect do exist.

There are a few examples of countries in receipt of development assistance which do themselves have excellent policies in place to promote the rights of disabled people. (South Africa is one such.) Much could be learned from these examples. In recent years the shift to rights-based development and the struggle of the disability-rights movement around the world to ensure that its voice is heard ('*nothing about us without us*' – Disabled Peoples' International) have led to an acknowledgement that practice does need to change.

In the UK, the Department for International Development published an issues paper in February 2000, entitled 'Disability, Poverty and Development'. It stated: 'Disability is both a cause and consequence of poverty. Eliminating world poverty is unlikely to be achieved unless the rights and needs of disabled people are taken into account.' There is a clear need to ensure that the most marginalised people are included in development work. This requires planners and all development workers to think multi-dimensionally, rather than to categorise people on the basis of single identities, such as gender, disability, urban/rural provenance, or HIV status. We need to be truly committed to diversity and to consider the whole person, remembering in our analyses that a disproportionate number of those experiencing social exclusion and poverty will be women, and especially disabled women and women living with HIV/AIDS. We need to look at the world through more than one lens.

However, until we are familiar with the institutional, environmental, and attitudinal barriers that exclude marginalised groups from full participation in society, we will be unable to ensure appropriate responses. That is why this manual is so important. It helps practitioners in development and humanitarian organisations to understand the issues confronting disabled children and adults, and ways in which we can go about breaking down the barriers and including people with disabilities in our work. It presents disability as a matter of human rights and moves away from the charitable and medical models of disability to argue that it is society that needs to change.

Disabled people themselves are powerful advocates for social change. Development practitioners need to hear the voices of disabled women, children, and men, in order to plan inclusive development.

Barbara Frost
Chief Executive, Action on Disability and Development

Preface

Oxfam's mandate is to overcome poverty and suffering. As this manual makes very clear, all around the world disabled people are among the poorest and most marginalised members of their communities. We need to understand why this is, and to devise ways of supporting them to take action to overcome their poverty and achieve their civil, political, social, and economic rights.

Disabled people, and particularly disabled women, are among those least likely to escape from the trap of poverty. Prejudice denies them the opportunity to develop the necessary skills, knowledge, and confidence, and to make effective use of the resources that they may already have. Many people working in development agencies are, often unwittingly, guilty of discriminating against people with physical or mental impairments, and disabled people are therefore less likely than others to benefit from development interventions – for the very same reasons that explain why they are poor in the first place.

This means that people with impairments are likely to remain among the chronically poor, and when progress towards the Millennium Development Goals is measured in 2015, it will be interesting to see how many disabled people are among those who have been enabled to edge above the poverty line.

Disabled people are often made invisible by society, and invisibility can be lethal in situations of armed conflict or natural calamity. Organisations such as Oxfam must enlist the support of people with disabilities in designing and delivering their humanitarian responses, if they are to ensure that all people are able to benefit equally from them. We have some excellent examples of good practice in this regard, but we cannot afford to be complacent. This manual identifies some of that good practice and helps us to understand how to replicate it.

It is only relatively recently that disability has been considered as an issue to be taken seriously by development or humanitarian agencies. Now, when major institutions such as the World Bank, the European Commission, and the British government's Department for International Development are making explicit their analysis of the relationship between disability, poverty, and the abuse of human rights, Oxfam GB and Action on Disability and Development (ADD) offer this practical toolkit for disseminating that analysis more widely.

In this era of globalisation, one of Oxfam's priorities is to ensure that the relationship between local and global causes of poverty is understood, and that the capacity of our

partners to address these causes at every level is increased. Among those partners, we are fortunate to count disability-rights organisations which have had some notable successes in this regard: campaigning and advocacy have resulted in legislative change in Albania, Kosovo, Lebanon, and Uganda, for example. The struggle continues, however, to ensure that laws are implemented and that disabled people actually benefit from them.

The Disability Movement, like any movement of people marginalised because of their identity, needs allies and deserves the support of development and humanitarian organisations. There is a growing realisation that rights-based approaches to overcoming poverty and suffering are essential, but awareness of the abuses endured by specific groups in this regard is often low. People working in the fields of development and relief often assume that they need specialist skills in order to work with disabled people, but a good start can easily be made by ensuring that we apply our existing skills and principles to the task.

I am pleased to introduce this, Oxfam's fourth book about the rights and needs of disabled people, and its second publication in collaboration with ADD, in the hope that it will help to raise awareness of these vital issues among workers in development and in the fields of humanitarian protection and response.

Barbara Stocking
Director, Oxfam GB

Acknowledgements

Abbreviations and acronyms

ADD	Action on Disability and Development
CBR	community-based rehabilitation
DETOT	Disability Equality Training of Trainers
DFID	Department for International Development
DPI	Disabled Peoples' International
DPO	disabled people's organisation
HI	Handicap International
INGO	international non-government organisation
KAPP	Kosovo Association of People with Paraplegia (now known as Handikos)
LAG	Local Active Group
NGO	non-government organisation
UDHR	Universal Declaration of Human Rights
UNDP	United Nations Development Programme
UN	United Nations

Introduction

This manual is derived from the experience of working with a disabled people's organisation originally known as KAPP (Kosovo Association of People with Paraplegia) and later renamed Handikos, which was supported by Oxfam GB in Kosovo between 1994 and 2001. Although the programme operated within the particular political and social context of Kosovo – a UN Protectorate located in south-east Europe – the challenges that it confronted are typical of those encountered by development and humanitarian organisations in many countries when they seek to respond to the special needs of sub-groups within a diverse population.

Over time, agencies have become more attuned to the concerns of vulnerable groups who will not necessarily benefit from generic, across-the-board approaches to meeting basic needs. The needs of women, children, orphans, older people, and ethnic minorities are now frequently considered when any intervention is being planned: it is an accepted fact that these groups may have specific problems of access which must be addressed if they are to benefit from the project. Less regularly, although the issue is equally pertinent, the particular needs of disabled people in a community are considered, and measures are taken to allow for their inclusion.

The work done by KAPP/Handikos, in partnership with Oxfam, before, during, and after the recent crisis in Kosovo, enabled both partners to learn from the reality of disability-focused work based on the principles of equality and empowerment. Theoretical models were compared with the actual situation of disabled people, and responses were developed to include disabled people in the definition and delivery of programmes to meet their needs. The cornerstone to this inclusive approach was the social model of disability and the application of Disability Equality principles. Useful lessons were learned about the process of changing attitudes towards disability, both within a humanitarian and development agency (Oxfam) and in the beneficiary community. This manual seeks to distil the theory and practice used in the programme. It also provides extensive details of methods and materials that were used as part of a training programme to raise awareness of disability.

Why this manual?

Worldwide, the current *status quo* for disabled people can only be described as 'disability inequality'. Humanitarian and development organisations have failed to ensure that disabled people are equal participants in their programmes. For agencies whose mandate requires them to reach those most in need, the (often inadvertent) exclusion of disabled people means that many organisations are currently failing to

honour their obligations. Disabled people are among the poorest of the poor, and the most powerless in virtually every community in the world. Programmes which do not include them on an equal basis with their non-disabled counterparts are inherently ineffective.

This book's basic premise is that the time is right to improve the *status quo*: Disability Equality must become part of the everyday reality of humanitarian and development work. If communities and organisations are to benefit from becoming disability-aware, and if disabled people are to be empowered to participate on an equal basis, existing ways of thinking and working must change. This manual provides information and training materials which will support this change.

It is important to emphasise, however, that the book is a starting point, rather than a definitive prescription. One of the reasons for publishing it is that the authors believe that Oxfam GB, like most other aid organisations, is seriously inadequate in its knowledge of and response to disability issues. The manual reflects Oxfam GB's commitment to improving its performance on disability, but Oxfam GB does not claim expertise on the subject. The text has benefited from contributions by ADD (Action on Disability and Development), which is the only British-based agency supporting self-help development work exclusively with groups of disabled people in Africa and Asia.

There is an urgent need for a manual such as this. In 1995, when Oxfam staff began to support the introduction of concepts of Disability Equality in Kosovo and Banja Luka, they could find no single publication which brought together, in one easily obtainable and simple-to-use resource, the materials that were needed. Existing materials on disability either lacked a rights-based approach, or they did not focus on group work or workshop activities, or they failed to take gender into account. Most literature on disability either views it from a Northern perspective or perceives it in exclusively development-related terms, rather than seeing it as an issue that is integral to both humanitarian and development work. Existing materials on human rights and gender (both theoretical and practice-based) pay scant attention to the existence and rights of disabled people. Disability issues are not covered at all, or they are inappropriately covered. Most training and group-work activities make the assumption that all participants are non-disabled.

Gathering and creating the materials while working in a geographically and technologically isolated area was a fascinating process, but it took a lot of time and effort. In order not to reinvent too many wheels, staff borrowed heavily from other sources and adapted existing materials to suit the circumstances. The training materials that form Part Two of this manual present the results of this labour and the lessons that were learned by using the materials.

The geo-political context

Can lessons learned from programmes in Europe be applied to other countries, especially developing countries of the South? For aid workers with experience of, say, Africa or Latin America, but not of Bosnia or Kosovo, this is a very legitimate concern.

In response, one could argue first that, while details differ from society to society, the root causes and effects of the poverty and marginalisation of disabled people are similar worldwide. And there are many commonalities in the range of responses which can lead to positive change. This is borne out by reviewers' comments on the first draft of this book, and contributions included in the manual from diverse countries, including Uganda, Bangladesh, and Mali.

Second, it is a mistake to see 'Europe' as a homogeneous entity. On the one hand, abject poverty can and does exist in this so-called 'developed' continent (and disabled people are very likely to be found in the most impoverished sectors of the population). On the other hand, war is – in an obscene way – a great leveller. Some newly arrived aid workers in Bosnia were shocked to see refugees wearing fashionable clothes, and intimated that these people, dressed like that, could not be 'real' refugees. But if those are the only clothes you have, what else are you supposed to wear? These people were still refugees: they had lost everything, apart from the one set of clothes they happened to be wearing when they were forced to leave their homes. You cannot eat fashionable clothes – you cannot even sell them at market to buy food, if (a) you can't get to the market for fear of being shot by snipers, (b) no one else has money to pay for them or wants to exchange anything useful for them, and (c) there is no food to buy or barter. And in sub-zero winter temperatures, one set of clothes, no matter how fancy they are, is not going to provide adequate warmth when there is no source of heating. In war-torn Bosnia, people died from hypothermia, pneumonia, and numerous other normally avoidable causes, irrespective of whether they lived in large houses or bombed-out high-rise flats or makeshift shacks. The lesson is that aid workers should avoid making instant value-judgements, and instead base their assessments on objective and informed criteria.

As with the experience of disability, the experience of being a refugee may differ in the details from country to country, but the fundamental experience of exposure to extremes of violence, fear, loss, trauma, and bereavement is very similar worldwide.

Navigating this manual

The manual begins with four narrative chapters. Chapter 1 presents the thesis and underlying principles of Oxfam's approach; to illustrate them, it offers an overview of the situation of disabled people and draws from Oxfam's programme experiences in Kosovo before and during a period of acute conflict. Chapter 2 outlines the principles of Disability Equality and illustrates its importance for development and relief agencies. Chapter 3 describes Oxfam-supported work with disabled people's organisations in Kosovo, and its outcomes. Chapter 4 provides a rationale for Disability Equality training and emphasises its importance for development and humanitarian agencies. Lessons learned in Kosovo and elsewhere are suggested as guidelines for good practice.

Part Two of the manual consists of a description and analysis of the Disability Equality Training of Trainers Course run in 1997 in Kosovo, the materials for which form the basis for the materials presented in this manual. This is followed by an introduction to the training materials, and the materials themselves – workshop activities,

facilitator's notes, and handouts. The two central themes are 'Acquiring Facilitation Skills' (commonly known as 'training of trainers') and 'Disability Equality'. Other training sections cover preparations, introductions, energisers, and forming the group; action planning; evaluations; and useful quotations.

The manual ends with some sample workshop agendas and a brief list of useful resources. The conclusion offers some final thoughts on the impact of initiatives to promote the rights of disabled people.

Parts One and Two form a whole text which aims to start from a Disability Equality perspective, to include (but not focus exclusively on) gender issues, to be applicable to work in emergency-response and development situations, to make learning accessible and empowering, and to fill the gap in the literature and avoid further duplication of effort.

Who can use this manual, and for what purpose?

The manual is designed to be used by two distinct sets of readers:

- Local or national disabled people's organisations, seeking to raise awareness and put Disability Equality into action among their membership and the broader community.
- The humanitarian and development community (from donors to implementers) and government staff, seeking to promote Disability Equality, whether internally within their own organisations or externally with programmes and beneficiaries.

The narrative and theoretical chapters, the training materials, and the background reading materials may be used by disabled and non-disabled people, and international and national staff, in the following ways: to inform and develop field work in emergency-relief or development situations; and to design courses, seminars, workshops, informal discussion groups, etc. The participants (or beneficiaries) could be disabled and/or non-disabled people; national and/or international staff, volunteers, members, or activists; members or staff of grassroots organisations, or national and international NGOs and agencies; local and national community leaders, educators, medical staff, civil servants, and so on.

The materials may be used to introduce or increase awareness of Disability Equality and support its practical implementation; to help disabled people to (re)gain self-esteem and confidence; to train disabled and non-disabled disability-rights activists; to encourage NGOs to consider disability in relation to the work of a group of women survivors of violence, or the work of reconstruction engineers, public-health workers, and other sectoral staff; and to teach others how to facilitate Disability Equality workshops or discussion groups. The development of local networks of facilitators is important in countries where there is a lack of Disability Equality trainers, especially those who are disabled. Beyond the contexts listed above, Part One of the manual may be read by individuals who want to find out more about Disability Equality and its relevance to their lives and work.

The manual may be read in its entirety, but we appreciate that busy readers will select certain sections that seem most relevant to their work. We have tried to write with this in mind, repeating some information where it seems necessary, and directing readers to additional information in other sections of the manual.

A frequent problem with relief and development publications is that, while usually much attention is paid to the abstract theory, the principles applied, and the conclusions to be drawn, the reader is often left thinking: 'Yes, I understand all the theory and principles, but what did you actually do? How does that work out in practice? What was the actual process that you went through in order to reach these conclusions?' Therefore, one of the aims of this manual is to present the theory and principles of Disability Equality, which are universally applicable, but also to relate the theory and principles back to specific settings and real examples – from Kosovo, Ghana, Cambodia, Bosnia, and elsewhere. Not in order to say 'this is the way to do it' (because there is no one 'right' way), but as a reference point, or a stimulus for comparison, analysis, and application to different settings.

Finally, we hope that this manual will provide an example of how, when social change is on the agenda, it does not matter that there never seems to be an optimum time to get started, or a perfect way of doing things. Whoever we work for – DPO, NGO, donor agency, etc. – the problems are the same. Very often the planning and practicalities are all wrong: there is too little money, not enough time, not enough staff, too much external interference. Maybe we know in advance that the results are not going to be spectacular (how can one adequately measure how someone feels about being alive, and the changes that result in his or her life?). But if we wait until all the conditions are perfect, we will be waiting for ever. Doing the best we can, whatever the circumstances, and focusing on the principles and process, as much as on the end product, is enough to make a start. And once the start has been made, who knows where the process will lead us?

A note on language

Language carries intent: how we think about someone or something is reflected in the language that we use, and this is translated into action. In addition there is a huge difference between attaching a label to another person and choosing how to describe and name oneself. One action disempowers, the other empowers. Across geographical borders which share a common language, and within a country, there may be differences in the terms that people choose as appropriate for themselves. For these three reasons we have consciously used and not used specific words related to disability in this manual, according to prevailing opinion within the disability movement in the UK.

We hope that this will not be confusing to readers from other countries, and for clarification we recommend reading the sections in the training materials on language and definitions of disability (section 9.5). Briefly, we use the word '*impairment*' when we want to talk about someone's physical, sensory, or developmental limitations, and '*disabled*' and '*disability*' to talk about the dis-abling experience that constitutes everyday life for people with impairments, due to society's

prejudices and discrimination. North American readers, please note that we have used the following UK-accepted terms:

- '*disabled people*', in place of the US term '*people with disabilities*';
- '*learning difficulties*' as it is understood in the UK, which is a broader definition than in the USA and includes all types of developmental impairments such as Downs Syndrome and 'retardation' (a term that is still surprisingly and commonly used in the USA), in addition to impairments like dyslexia, Attention Deficit Disorder, etc;
- and '*disability rights*' in the broadest sense of rights – encompassing human rights and basic rights, as well as legislation and social security.

One area where there is no wish to show intent through the choice of language is the spelling of 'Kosovo' (as opposed to the Albanian-language Kosova or Kosovë), used throughout this book. With the polarisation brought about by the political crisis, the way in which one spells and pronounces the word can be interpreted as a statement of one's allegiance to one side and an insult to the other. This is not the intention. We use 'Kosovo' with no political intent in any sense, and purely because it is the commonly accepted English-language spelling of the word.

Hopes and fears

This introduction would not be complete without some provisos about the manual. Firstly, in order to try to say anything at all about such complex issues, which no two people, in a variety of complex circumstances, will experience identically, we have had to make some generalisations. We have tried to make them as accurate and representative as they possibly can be; but in the knowledge that generalisations always end up excluding or offending some people, we ask for tolerance and understanding.

A significant shortcoming of this manual is that it is not written in such a way as to be accessible to many people with learning difficulties for their direct use. As a start, what the manual can and does try to do is to include consideration about how the issues of rights and equality relate to people with learning difficulties, and to prompt non-disabled people and people with physical and sensory impairments to think about this. The experience of the disability movement shows that change will come most effectively from disabled people themselves. This process can start with people with physical and sensory impairments becoming politicised, working together across the spectrum of impairments, and supporting people with learning difficulties to become actively involved. But it does not always happen this way, and there is also a need to support groups of people with learning difficulties to organise, speak, and act on their own behalf.

Many people contributed to this book in various capacities: as relief and development workers, as members of disabled people's organisations, and as disabled and non-disabled individuals. This made it hard to find a consistent voice in which to write: who is 'us' and who is 'them'? Using the first person would have made the text more immediate and accessible in tone, but might also have confused the reader. So in the

end 'we' wrote it all in the third person (with the exception of this introduction). We apologise if this results in a certain dryness.

Lastly, we see this manual as a starting point, not the final product. We believe that it constitutes a powerful tool for change, even though it is shaped from a relatively limited range of experiences. We hope that readers will be inspired to use it and, with broader application and adaptation, improve it.

Part One

The principles of Disability Equality training

1 Disability and development:
an overview of the issues

Defining disability

What is disability? Trying to define it is a complex and controversial matter. It is important to consider the preferences of disabled people themselves, and to bear in mind that acceptable terminology changes over time, and from one culture to another. Two key terms – 'impairment' and 'disability' – are often used synonymously. However, their meanings are different, and it is important to make a distinction between them. **Impairment** has been defined as *'lacking all or part of a limb; having a defective limb, organ or mechanism of the body'*.[1] Some disabled campaigners question the use of this term, because of its negative implications; they prefer the more neutral term 'condition'. A condition may or may not be perceived as an impairment and may or may not restrict one's ability to function.

In contrast, the term **disability**, as used by disabled people's organisations (DPOs), emphasises society's denial of the human rights of the person with the impairment. In the words of Disabled Peoples' International: '*Disability is the disadvantage or restriction of activity caused by contemporary social organisation, which takes little or no account of people who have impairments, and thus excludes them from the mainstream of social activities.*'[2]

The distinction between the two terms is neatly summarised in a discussion paper issued by the UK government's Department for International Development: '*Disabled people have long-term impairments that lead to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community.*'[3]

Societies may differ in their treatment of disabled people or in the way in which discrimination is expressed, but in general the marginalisation of disabled people is international and irrespective of social class.

Three major types of discrimination have been identified: **attitudinal**, **environmental**, and **institutional**. Disabled people may be socially excluded by attitudes of fear and ignorance on the part of non-disabled people, who may use negative and pejorative language about them; or they may be excluded from society because of generally low expectations of what disabled people can achieve. Environmental discrimination occurs where public services, buildings, and transport are not designed with access for disabled citizens in mind. Institutional discrimination occurs where the law discriminates (explicitly or by omission) against the rights of disabled people, making them in some way second-class citizens – without the right to vote, to own land, to attend school, to marry and have children.

'Disabled people want to be treated as normal citizens, with rights. They want to be treated equally and participate as equal citizens in their own communities. To achieve this, you need political and social action to change society.'[4]

The prevalence of impairment

The United Nations Development Programme (UNDP) estimates that in 1990 one in 20 of the world's population had a moderate to severe impairment (either physical or mental); the proportions ranged from 4.5 per cent in 'developing' areas to 7.7 per cent in 'developed' countries. The World Health Organisation, surveying the whole range of impairments, from mild to severe, estimates that between 10 and 15 per cent of the population of 'developing' areas are affected, with higher levels in affluent countries.[5] Detailed surveys indicate wide variations in the prevalence of impairments within and between countries, depending on a range of factors. For example, endemic river-blindness may affect many people within a particular area; in populations with large numbers of older people, conditions caused by the normal process of ageing are more prevalent; where armed conflict has included use of anti-personnel mines in rural areas, exceptionally high numbers of amputees may be found.

High mortality rates among children and young people with disabilities reduce the recorded incidence of impairment; yet, even if those who have died prematurely are excluded from the estimates, disabled people form a substantial minority of any population. If, in addition, we consider the families of disabled people, their carers, and others who are seriously affected by disability, then in some parts of the world the majority of the population may be affected by disability.

Disability, gender, and poverty

There exists a vicious cycle that links poverty and disability. Poverty frequently causes disability, or makes its effects worse, by virtue of factors such as malnutrition, inadequate housing, dangerous work in hazardous conditions, poor-quality medical treatment, and inadequate access to services. Disabled people are likely to face barriers to their inclusion in society, to educational opportunities, and to their access to health care and employment, which in turn will perpetuate their poverty. Families with a disabled member also face barriers and are likely to experience a greater degree of poverty than similar families without disabled members.

The need to care for a disabled family member makes demands upon other members and reduces the time available to them for economic activity or skills development. Disability has a disproportionate impact on males and females: in developing countries, most of the caring, as well as much of the production, is done by women, and girls are frequently withdrawn from school to look after a disabled brother or sister. Although in global terms 51 per cent of disabled people are women, disabled girls and women have even less access to education, health care, and employment than disabled boys and men have. Disabled women are doubly discriminated against: as women, and as people with impairments. They are often invisible to the providers of health care, and particularly reproductive-health care, yet they are also the frequent victims of sexual abuse.

While it is true that poverty is the cause of many impairments, disability affects rich and poor people alike. In Kosovo, there is a myth that people who are educated, wealthy, or professionally qualified take better care of disabled family members than people who are poorer or less educated. In reality there may be more pressure on a wealthy family to hide a disabled relative, so as not to damage the family's social status. Oxfam found that disabled people and their families who were wealthy or belonged to the social elite were less likely to become involved in disabled people's organisations, whereas people who were really struggling to survive became very active, both as contributors and beneficiaries.

Discrimination against disabled people is compounded if they belong to an ethnic minority or other marginalised group. But irrespective of their social class, or their religious or ethnic identity, disabled people around the world are likely to be poorer in terms of money, power, and rights, than non-disabled citizens of the same group.

Organisations *for* disabled people and organisations *of* disabled people

Throughout Eastern Europe, under the socialist system, State-funded associations based on types of impairment (blindness, paraplegia, etc.) catered for disabled people. They gave people access to orthopaedic equipment, State welfare benefits, and occupational therapy, but they resulted in the segregation of services for disabled people and did nothing at all to empower them to claim their rights. Once the socialist system collapsed, even welfare benefits were lost, with nothing to replace them.

In the absence of a strong civil society, there was no mechanism for disabled people to participate in and lobby for changes that would improve their conditions. On a fundamental level they were not represented in forums where they might have claimed their rights and expressed their needs, and as such they were disenfranchised from the State process. In Kosovo the problem was compounded by prevailing attitudes of rejection or shame, which meant that disabled people were either hidden away and left to die, or cosseted and over-protected, deprived of any opportunity to live independently. The net result was that disabled people were virtually invisible and lacked mobility, opportunity, and confidence. Disabled women experienced these problems even more keenly than disabled men.

In all societies, many families respond to disability by being over-protective. They rarely allow disabled family members to go outside the home, in case they get hurt or ridiculed. Everything is done for the disabled person, including things that he or she would be perfectly able to do independently. The effect of this over-protectiveness, usually motivated by love, is to render the disabled person passive and inactive, and to feel helpless and patronised. Denied the freedom to take risks and responsibility or to learn from mistakes, he or she is permanently treated as a child, and not allowed to grow up.

None of these problems is unique to Kosovo, but in a highly politicised environment it is particularly difficult for disabled people to articulate their specific needs, as distinct from the needs of the whole community. Throughout the 1980s and 1990s, tensions grew between the Kosovo Albanians and the Belgrade government. This evolved into a full-blown conflict in 1998. The prevailing view in Kosovo was that the situation of disabled people would automatically improve if and when the political problems were resolved for the whole population. The needs of the minority were subjugated to those of the majority – but many of the problems that disabled people faced were not at all dependent on a resolution of the macro-political problems.

Well-meaning professionals and carers have for many years decided what opportunities and services are offered to disabled people. Organisations for various disability sub-groups have tried to complement State provision by running additional services, such as organisations for blind people, or deaf people, or those with limited mobility. Whether run by the State or by the voluntary sector, both these approaches have been based on addressing the special needs of disabled people, particularly those closely relating to their impairment.

 In recent decades, disabled people have reviewed the progress made towards meeting their needs via this model of service provision, controlled and organised by non-disabled staff with little room for the inclusion of the end-users. Since the International Year of the Disabled Person, 1981, and the ensuing Decade of Disabled People (1982–1992), disabled people and their own organisations have played a critical role in speaking out in international forums about the specific needs of disabled people, and in developing a rights-based approach to disability. This approach assumes that disabled people have diverse needs, like those of non-disabled people, which should be met as part of the general provision for the whole population: education services should meet the needs of all students, whether disabled or not; health services should be open and accessible to all.

The global, cross-disability movement called Disabled Peoples' International (DPI), to which most national organisations belong, describes itself as 'the last civil rights movement'. Its motto is *Nothing about us without us.* This is a call to disabled people and their organisations for action, involvement, and commitment. It urges disabled people not to allow others to ignore or forget about them, but to consult and listen to them, and to take their needs and rights into account. It encourages disabled people to make their presence felt and their opinions known, and to be actively involved in making decisions about all the issues affecting them.

Three models of disability

A major contribution made by disabled people to an understanding of disability has been the description and development of 'the three models of disability'. These are frameworks which help to explain the ways in which society responds to disability and to review the appropriateness of its responses.

The medical model of disability

The medical model tends to view disabled people first and foremost as having physical problems to be cured. The disabled person is relegated to the passive role of patient, with medical personnel and care professionals making many decisions – even about issues unrelated to impairment, such as how the individual should dress or what he or she may eat. This model is problematic because of its excessive focus on the desirability of fixing the disabled person's impairment. The quest for a cure is often protracted, painful, and unnecessary; it means that the rest of life is put on hold while professionals strive to return the body to a more 'normal' level of functioning. Corrective surgery is used to extend and straighten limbs, callipers are applied, and people are encouraged to try to walk, rather than use wheeled mobility appliances; deaf people are taught to speak and lip-read. Health-care professionals may refuse to tell disabled patients and their families that there is no cure for their condition, in the mistaken belief that this will sustain hope that they one day might be 'normal'. But if it happens that the impairment cannot be fixed, the disabled person is regarded as being beyond hope: his or her life is seen as worthless. By this stage, such a negative assessment may well become internalised by the person concerned.

There are clear cases where relatively simple levels of medical intervention can reduce the impact of impairments substantively; examples would be a surgical operation to correct a cataract or a club foot. It is also the case that some disabled people have a medical condition which requires support and intervention. Preventive measures to reduce the incidence of impairment and to promote its early detection are also valuable means of reducing the level and impact of disability. Disabled people do not reject medical intervention, but they stress that the impact of disability on the individual is much greater than its medical implications, and that it is misleading to focus on the search for a cure, rather than helping individuals to manage their own lives.

The medical model perceives disability as a problem located in the disabled individual, and assumes that working on the individual can solve it (or not, as the case may be, in which case the person concerned might as well give up all hope of a full and satisfying life). The disabled person becomes defined solely in terms of his or her diagnosis, as a patient with medical needs and no longer as a person with a whole range of needs.

One young woman from Kosovo described the sense of liberation that she felt when, after many failed operations to lengthen one leg by 3 cm to make it the same length as her normal leg, she finally decided that this was unimportant. She and her leg were fine as they were. She turned her back on medical interventions and got on with the rest of her life: she became a hairdresser and beautician, building up a fine reputation, and now brides come from far away for her wedding make-up service. During the pre-war years of political and economic crisis in Kosovo, she supported her family from her own income.

The religious, or charitable, model of disability

In Kosovo, disability is traditionally interpreted according to religious beliefs: impairments are regarded as a punishment from God for a sin committed by oneself or one's family. Having a disabled relative is a source of shame, often for the whole family. Disability can damage the marriage chances of non-disabled siblings, especially sisters. Consequently, some families keep their disabled relatives hidden from neighbours, visitors, and even other family members. Some disabled people live out their existence, such as it is, isolated in one room, at times even chained up.

The religious, or charitable, model tends to view disabled people as victims of impairment and as the beneficiaries of charity, alms, and services – for which they should be grateful. Disabled people are viewed as tragic or suffering people, to be pitied and cared for. At the same time, disabled people may find that they have few choices, no means of accessing relevant advice, and no powers to decide how they could best be assisted. Services are designed for them and delivered to them, perhaps with the best of intentions, but with insufficient consultation. Carers may become unacceptably powerful, making decisions about what is best for those in their care. An extreme (though not uncommon) example of this is the enforced sterilisation, without consultation or consent, of disabled women.

It is not uncommon for disabled people to become dependent upon the source of help, and for the alms-givers to gain gratification and reward from the relationship. Charity is provided at the discretion of the giver, often on the basis of 'worthiness'. If the person providing charity or care decides that the disabled person is unworthy, bitter, or 'negative', help may be withdrawn on a whim. Disabled people are often caricatured as being tragic and passive, if they need high levels of support; as bitter, twisted, and aggressive, if they are beginning to question the *status quo*; and as courageous and inspirational if they have managed, against all the odds, to overcome the barriers that confront them.

Because disabled people are considered to be different from the norm, a range of different, or special, services to meet their needs has usually been provided for them: special transport; special buildings; special schools (where the courses are very often less challenging and academic than in mainstream schools, making it hard or impossible for disabled people to enter higher education and employment); special sports and recreational facilities; sheltered employment workshops. Extra resources are necessary in order to provide such special services, and in resource-poor economies the inability to provide adequate levels of service (in health care, education, production) for the whole population is frequently used as a justification for doing very little to provide special services for disabled people.

It cannot be claimed that either the medical or the religious/charitable approach has had much success in improving the lives of disabled people – as proved by the high levels of poverty, abuse, marginalisation, and discrimination that disabled people still face worldwide; yet for centuries these two models have determined disabled people's

experience. Through what is known as the 'mirror effect', many disabled people (who, like others, see themselves reflected in the attitudes of the people around them) have come to believe that they are *unable*. In recent years the deliberate focus of the disability movement on abilities rather than inabilities has helped to develop a new understanding of disability. In order to create a society that includes disabled and non-disabled people equally, and thus achieves Disability Equality, we need a new way of perceiving and responding to disability.

The social model of disability

Such a concept and approach is described by disabled people themselves as 'the social model'. This refers to the way in which society organises itself, taking little account of people who have impairments and thus excluding them from participation in the mainstream of social activities. The social model identifies three major barriers that confront disable people who have impairments: physical (exclusion from the built environment), institutional (systematic exclusion or neglect in social, legal, educational, religious, and political institutions), and attitudinal (negative valuations of disabled people by non-disabled people). Removing these barriers is possible and has a hugely beneficial impact, both on the lives of disabled people and on the whole community.

Adopting the social model of disability does not mean rejecting any form of medical services, rehabilitation, or assistance from others; but it does change the way in which services and assistance should be given, placing them in the wider context of disabled people's lives. Disabled people's needs are basically the same as non-disabled people's: for life, love, education, employment, full participation in society, access to adequate services (including medical and rehabilitation services when necessary) as of right, and some choice and degree of control in their lives.

> 'We cannot give the blind person sight. We can give the sighted person the ability to enable the blind person to do what s/he wants.'[6]

The social model has allowed many disabled people to regain control of their own lives, becoming the experts on their own experience and changing their outlook in fundamental ways. An understanding of the social model provides a radically different framework with which to understand the discrimination that arises as a result of impairment. For many DPOs, the social model describes the true nature of the problem of disability. The problem is not in the individual, nor in his or her impairment. The impairment exists, but its significance is neutral – neither necessarily negative or necessarily positive. The problem of disability lies in society's response to the individual and the impairment, and in the physical environment, which is mainly designed (largely by non-disabled people) to meet the needs of non-disabled people. Disability takes on a social dimension and leads to social exclusion and the denial of human rights. The solution to the problems of disability must therefore come from change within the families, communities, and societies in which disabled people are living, rather than from changes in the impaired individual (as suggested by the medical model).

The social model is a helpful tool to enable disabled people and their allies to achieve positive changes in their lives, and for non-disabled people to understand more about disability. There are similarities between the claims made by disabled people and those made by other civil-rights movements, such as the campaigns for the rights of women, ethnic minorities, and people of different race. The disability movement has learned from other liberation movements that change has to start with action by the oppressed: in this case by disabled people themselves. They are the experts of their own experience, and they best understand how society is organised around the needs of its non-disabled members. Disabled people internationally are now gaining an increasing voice – articulating their own needs, taking an active part in meeting them and in lobbying for full inclusion in society. Non-disabled people share responsibility for changing attitudes, shifting positions, and making changes that will allow fuller inclusion of disabled people. Many non-disabled people play an important role as allies, understanding and supporting disabled people's struggle for equal rights and being prepared to make concessions in their own positions.

> When I adopted the social model as a lens through which to see my life, I realised it brought with it certain responsibilities. No longer could I claim victim status at the mercy of the non-disabled community. I had now found a way of dealing with society's treatment of me. I had a tool, which enabled me to redefine my experience. I now had a terminology and the language of oppressed people, which enabled me to belong and struggle against society's attitude towards me. At best we face society's ignorance and at worst we face their apathy towards the discrimination of disabled people in our daily lives. With others who think the same, and there are many, I now had the responsibility to try and do something about it. (Liz Crow, quoted in E. Boylan: *Women and Disability*, London: Zed Books, 1991)

Disability in the context of development

In the community-development field, the most common approach to disability emphasises rehabilitation, whether institutional or community-based. Integral to the medical model, rehabilitation frequently appears to address only a limited number of the needs of disabled people – in particular mobility aids, communication skills, and skills for daily living. No one would deny that these aids and skills can make an enormous difference to the quality of life and independence of disabled people, but their acquisition is not an end in itself: it is merely the first essential step towards enabling disabled people to gain access to all other services. The development community often fails to address the full range of disabled people's needs and rights, which are far more diverse than these most basic needs. For example, credit and income-generating schemes should not exclude disabled people by fixing criteria for inclusion – such as minimum land tenure or possession of fixed assets – that will automatically disqualify disabled people, who in general lack such resources.

The way in which rehabilitation services are delivered, predominantly by health-care and social-work professionals whose experience and outlook are strongly influenced

by the medical model of disability, is problematic. Much has been made of so-called 'community-based rehabilitation' (CBR), which is an approach designed to deliver rehabilitation services through accessible and cost-effective mechanisms. But its implementation differs in almost every situation, and in its narrowest sense CBR is simply rehabilitation which has moved out of institutions, to be delivered in the community according to a template defined by the manual of the World Health Organisation. A more inclusive approach is evolving from a community-development approach to CBR, and some exceptional CBR programmes have been implemented with the full involvement of disabled people, their families, and their communities. The principles of rights, equal participation, and inclusion have now been recognised in some CBR programmes, but they still frequently appear as add-on extras, rather than as integral principles from which the whole approach is elaborated.

Current attitudes and approaches should be reversed to allow disabled people to participate in the definition of their needs and the design of projects to address those needs, and to include them in the management of systems to deliver benefits. Obvious parallels may be drawn with the inclusion of women as beneficiaries and as organisers of development activities to address the needs of women. The basic development principle of involving beneficiaries in identifying and prioritising needs, in influencing decisions about a range of possible solutions, and in managing and monitoring project activities (in other words, participation, consultation, and feedback) should be respected in all interventions intended to benefit disabled people.

Many agencies now argue for a twin-track approach to disability, suggesting that while it is still necessary to run development activities designed to address particular needs of disabled people through sector-specific projects, such as the provision of wheelchairs, hearing aids, and hygiene facilities, it is also vital to address disability as a cross-cutting theme, considering the needs of all sectors of a diverse population in generic development projects (for example, delivering good-quality health care and clean water to all). Ideally, all development staff should automatically consider the needs of disabled people within their target population – applying a Disability Equality dimension to the initial project analysis, so that disabled people are expressly included in the beneficiary group, rather than excluded by omission.

Mainstream development programmes may inadvertently discriminate against disabled people and exclude them if they do not apply a Disability Equality analysis. For example, in Uganda most micro-finance programmes set preconditions that are too onerous for disabled people to meet (since they are usually among the poorest in their communities). One livestock-distribution programme requires beneficiaries to own at least one acre of grazing land. According to local tradition, disabled people are not allowed to inherit land and are thus automatically ineligible for inclusion in the scheme. If staff responsible for identifying potential participants in any programme are not aware of the needs and capabilities of disabled people, they may bring their own prejudices into decision-making. If they focus on disability and not ability, they are likely to believe that disabled people are inadequate and assess them as a bad risk.

An approach to disability based on the social model is well illustrated by the 'Come To Work' programme in Bangladesh, as described by one of its participants.

'My name is Sufia. I am 52 years old. I live in a small village called Chak Krishnapur. My husband was a poor agricultural worker. He died about 12 years ago. I have seven daughters and one son, who are all married now. I started working as a day labourer in a rice-husking mill after my husband's death. My employer and colleagues said I was a sincere and hard worker. But one day an accident occurred: my sari (garment) got caught in the moving belt of the husking machine, and my life was changed. I lost my left hand and became disabled. I lost my job and became unemployed. I saw everything dark around me and became dependent on others. People were sympathetic, but I did not like their attitudes. I cried every night, could not sleep, and could not see how I would survive.

One morning a woman from Come to Work (CTW) came to meet me and described their activities. She suggested I join the CTW women's group, and said that my disability was not a barrier to joining the group. I started dreaming again after talking to her. I joined the nearest women's group, called Chak Krishnapur Mahila Samity, and started to generate savings. The other members accepted me and were very co-operative, helping me to learn a lot, including the rules and regulations of the credit scheme.

Within six months of joining the group, I got Tk. 500 credit from CTW for income-generating activities. I bought a goat, which produced two kids, and I made a profit. I repaid the credit to CTW and received Tk. 1500 to buy a cow. Gradually CTW increased my credit, and my income also increased. Now I own four cows, eight goats, 15 ducks, and five hens. I created all these assets from the profit on the credit-support provided by CTW. Now I have changed my life: I am not dependent on anybody.'

(As told to Shah Alam Liton, Oxfam GB, Bangladesh).

Disability in situations of disaster and conflict

In any crisis (whether it arises from war, or natural disaster, or political or economic upheaval), disabled people are likely to feel the negative impact of the crisis more keenly than other citizens. Their ability to cope and survive may be completely dependent upon others, and the capacity of any family to support its disabled members is keenly tested in a crisis. Anecdotal evidence from acute emergencies suggests that disabled people suffer particularly high rates of mortality and morbidity.

In conflict-ridden regions, there is always an increase in the incidence of impairment. In addition to those who were disabled before the onset of the crisis, many more become disabled as a result of a range of factors:

- combat injury and poor medical care behind the lines;
- mutilation used as a tool of war (for example, amputation of the hands of suspected government sympathisers by the Revolutionary United Forces rebels in Sierra Leone)
- land-mine injuries to civilians
- deterioration in medical services within a country in conflict
- interruption of preventative health-care programmes.

Within displaced and refugee populations, disabled people are frequently abandoned and left behind, to be killed by the enemy or to face starvation.

- They get left behind because they have no transport, because they cannot travel on foot over mountains, or because their families are unable to carry them.
- They get left behind because priority is given to the survival of non-disabled family members. (This is frequently the case for people with learning difficulties, for whom mobility is not even an issue.)
- They become more dependent, even totally dependent, on others, for food, water, assistance with basic bodily functions, and information.

Disabled people have additional and specific needs for protection. Anecdotal evidence from refugees indicates that in Sierra Leone soldiers would shoot dead on the spot any disabled people they came across, 'to put them out of their suffering'. Oxfam programme staff in Bosnia heard how disabled people became trapped in institutions during the war and starved or froze to death. An institution housing physically disabled people became caught between military front lines; staff fled, and the disabled residents all died.

In the words of Myrvete, a disabled woman activist from Kosovo: 'If a non-disabled person has one problem, a disabled person's problems are twice as big. For example, during the recent conflict, I've been working with disabled people from areas directly involved and I can't imagine how they escaped. I imagine them being carried by a family member and friends away from the shelling. Some were not so lucky: we know of a disabled woman who was killed because she couldn't move herself.'

People with impaired mobility who are able to flee may subsequently become more dependent because wheelchairs and other aids were left behind for reasons of space, or are not usable in the new environment. Visually impaired people may not be able to rely on their usual strategies for orienting themselves, both as they flee and when they arrive in places of temporary refuge. People with learning difficulties are known to be particularly exposed to risk, despite the fact that they have no direct mobility problem. For a disabled person who has never been allowed outside the family compound, fleeing may cause enormous physical and psychological trauma, and at the outset disabled people may be unable to assess the risks or make a choice about whether to flee or to stay.

Lack of understanding of the problems of people with learning difficulties (whose needs are often the last on the list of priorities, even among DPOs) often means that their need for psychosocial support and protection is overlooked. During the Krajina emergency in 1995/96, when Croatian troops displaced nearly 300,000 Croatian Serbs into Bosnia, Oxfam staff found people with learning difficulties left to fend for themselves, while others who were less vulnerable benefited from the whole range of available assistance. During the crisis in Kosovo, disabled people told Oxfam of their wish to leave their villages for a safer location, which was frustrated by their families' reluctance to move. Because disabled people in this environment were heavily dependent on their family, they were left with no choice over their own immediate future. At the other end of the spectrum, some disabled people were used against their own wishes by their families, who got permission to leave Macedonia on humanitarian grounds and seek asylum in other countries.

The vulnerability of the population as a whole is increased in a crisis; and, given the scarcity of resources, people's needs have to be prioritised. Those whose value to society is not recognised are given lower priority. In registering for assistance, displaced families may fail to indicate that they have a disabled member, which results in that person's general and specific needs remaining unmet. The disabled person may have to wait until everyone else in the family has been fed before he or she is provided for. Frequently the breakdown of support structures within a disaster-affected population further endangers the position of disabled people; they may lose their ability to function independently – and with it their dignity.

During the emergency in 1995 in Krajina, Croatia, a man with muscular dystrophy reached a temporary refugee reception centre. Before the conflict this man had lived in his own accessible apartment with his wife (who was also physically disabled). He had his own electrical repairs business and supported his ailing elderly mother and seven-year-old son. Since fleeing from home and arriving at the centre, this man virtually fasted – eating and drinking the bare minimum in order not to use a toilet very often. Because the toilet at the reception centre was completely inaccessible to him unaided, and it was very hard to find someone willing to help him, the indignity of his need was causing him to place himself at risk. If this man had become sick or died, the human loss and the care of his three dependents would have cost his community and those providing aid far more than the provision of a simple accessible toilet or toilet chair.

Disability within a relief context

The effects of an emergency, while significant for everyone concerned, are not equally felt. Long-held attitudes and established cultural norms determine who is valued in society, who deserves what, and who has access to power, decision-making, assets, and money. In emergencies this results in inequitable access to resources and services that should be basic rights, in favour of those with higher status. People who

are accorded lower status are therefore usually very vulnerable and exposed to a higher risk of suffering. It is widely accepted that in complex political emergencies the denial of human rights is very often at the heart of the crisis. It must also be recognised that the inequitable effects of the crisis – the fact that the impacts are harsher for marginalised groups than for other groups – are also primarily a matter of human rights. Relief and development workers are now recognising the disproportionate vulnerability and suffering of women and girls, but most have yet to recognise the particular problems of disabled people.

Disabled people tend to be invisible to emergency registration systems. They are frequently left unregistered, which means that they fail to receive their basic entitlements to food, water, and clothing, and their specific needs are not met either. Disabled people may lack the necessary documents which would give them refugee status and rights as returnees. This problem was particularly acute in Kosovo, where for ten years many children had not been registered (as part of the Albanian refusal to participate in structures that they perceived as part of the Serbian State). Disabled children were even less likely to be registered, which made it hard to prove their right of return.

Emergencies compound the dependence of some disabled people on their primary carers. For others, used to living independently, lack of appropriate responses in a crisis can create a situation in which they are forced into becoming more dependent on others. This was acutely obvious in the refugee camps in Macedonia in the late 1990s, where initially there was no provision at all for disabled people. They were not recognised in the initial registration system, and they were not provided with any facilities that would make their lives easier (accessible latrines, water points, levelled terrain, alternative means of access to information, etc.). This was in direct contradiction of the Red Cross and Red Crescent Code of Conduct, which recognises the essential dignity of each human being, and the importance of providing assistance that enhances and promotes self-reliance.

> In 1996 a survey organised by Oxfam in 13 municipalities in Bosnia identified more than 1000 disabled refugees and internally displaced people. The majority reported that the only aid they had received was very limited supplies of food, despite the existence at the time of a whole range of distribution and psychosocial support programmes. In addition, many were at increased risk of disease, due to the unhygienic conditions of their temporary accommodation (caused in large part by the inaccessibility of facilities) and their lack of access to medical attention.

It cannot be assumed that general distributions to the affected population will automatically reach the disabled members of that population, or that disabled people in a refugee camp will automatically have equitable access to whatever water is available. There are many reasons why disabled people are excluded, and unless agencies take specific action, things will not change. Common reasons why disabled people fail to receive their entitlements include the following.

- They are hidden by their families.
- They may not know there is a distribution, because they cannot attend community meetings or cannot hear radio announcements, and no provision has been made to inform them in any alternative way about their entitlements and the available services.
- Disabled people and their families may not consider themselves to be capable of participating in a micro-enterprise programme.
- Problems of access may be aggravated by poor terrain, or lack of mobility aids, or (for people with impaired sight) assistance with orientation.
- They may have become ill through not being able to keep clean, or through developing pressure sores in their difficult living circumstances, or lacking medication that they require.
- Emotional distress and/or mental illness, often caused by the trauma of the crisis, is another reason why people are prevented from gaining access to relief distributions for themselves and their families.

By including disability as a factor in assessments and using a variety of approaches to ensure that all people can obtain the relief to which they are entitled, it is possible to ensure that disabled people are included. Assessment and planning tools already commonly in use can be adapted to include disabled people; for example, participatory mapping processes should identify the locations of disabled people, and their particular resources and needs .

The post-crisis reconstruction phase

Major reconstruction often follows emergency relief work, but planners often miss opportunities to avoid recreating the inequitable *status quo* by adapting the design of the built environment to meet the needs of disabled people. For example, if schools are not rebuilt in a way that allows disabled children (both those who were previously disabled and the newly disabled) to attend school, this sends a damaging message to the disabled child and places limitations on his or her entire life. The long-term costs are high, since a disabled child who is prevented from going to school is far less likely to find employment and contribute directly to the national or local economy, and will thus require a lifetime of assistance from the State or his or her family.

It is often more cost-effective to modify the plans for a new building at the outset than to adapt an existing building retrospectively to make it accessible. Depending on the type of building, providing full access facilities from the outset costs an average additional 1.12 per cent (ranging from 0.1 per cent for public buildings to 3 per cent for individual family homes); for retrofits the additional cost has been calculated at 7.2 per cent (ranging from 0.12 per cent for public buildings to 21 per cent for individual family homes).[7] It is reasonable to expect that, as architects and builders become more experienced in incorporating elements to improve accessibility, costs will fall further.

To argue that accessibility is not cost-effective overlooks the fact that everyone, not just disabled people, will benefit from an accessible built environment. Older people,