

## **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*’.<sup>1</sup> 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.*’<sup>2</sup>

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.*’<sup>3</sup>

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.'<sup>4</sup>

## **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.<sup>5</sup> 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 hair-dresser 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 disabled 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.’<sup>6</sup>

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).<sup>7</sup> 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,

young parents with small children, those who are temporarily injured – a total of perhaps 40 per cent of the population – need the same sorts of access modification in the built environment. An accessible environment, designed to meet the needs of people with disabilities, is safer for everyone; it reduces the number of accidents, leading to long-term (but unrecognised) savings in health care and welfare costs, lost income, and so on.

### **The development of civil society**

Post-war aid programmes which support the development of civil society and help people to exercise control over their lives and to have a voice in their community must guard against excluding disabled people from this stage of the reconstruction process. It is important to consider the place of disabled people in those programmes and in the civil society that they aim to create.

Uganda provides an impressive example of how disabled people can be fully included in community and civic development. Ten years of sensitisation, lobbying, advocacy, and organising by disabled people, working together as a united movement, led to their representation within decision-making bodies at all levels of government. At the time of writing, Uganda had five disabled Members of Parliament, and 46,210 disabled people serving as Councillors from village to district council levels. Achieving political representation is, however, a means rather than an end: Uganda's disabled people are now set to challenge institutionalised barriers to equality from within the decision-making institutions of their communities.

During the war in Bosnia, disabled people's organisations were the only local organisations to maintain their pre-war membership without prejudice based on members' ethnicity. Resisting enormous social and political pressure to discriminate according to ethnicity, disabled Muslims, Serbs, and Croats helped each other to survive. This type of cross-cultural co-operation should be recognised by agencies implementing civil-society projects and should be seized upon as an opportunity and entry point for fostering further dialogue and active co-existence between peoples who were previously at war. During and after the war in Kosovo, disabled people's organisations played a vital role in providing emotional support to traumatised and displaced disabled people: another key element in the process of healing and recovery, without which it is hard for civil society to develop.

## **Disability inequality: the consequences for the relief and development community**

Despite the majority of UN member states being signatories to UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities,<sup>8</sup> these standards, which provide targets and guidance for the inclusion of disabled people in society and provide for equal access to services and participation, are rarely put into practice. There remains an enormous amount of lobbying and advocacy work to be done to encourage governments to address these issues and to reach the standards set out in this and other conventions.

Many disabled people are excluded from relief and development programmes as beneficiaries, partners, and contributors. Their basic needs are simply not adequately met, and their human rights are at best ignored, at worst abused. The exclusion or omission of disabled people has a negative impact on the quality and effectiveness of programmes. Disabled people are among the poorest of the poor, the most disempowered, and the most in need; they are present in virtually every community in the world, as well as in all populations targeted by relief and development interventions. It follows that many agencies are currently failing to fulfil their mandates.

Most emergency, relief, and development organisations are mandated to address problems of poverty, marginalisation, powerlessness, vulnerability, and abuse of human rights. These issues form the basis of many disabled people's daily experience, and yet too often there is a disparity between the mandate and stated operational philosophies of agencies, and what they actually do in practice to support disabled people in their struggle for equality. It is still not uncommon for relief and development agencies and donor institutions to be blind to disability or to ignore its impact when analysing a given situation and the needs of those who are most affected by poverty or emergency. Whatever the type of programme (emergency relief, or development) under consideration, the target population will almost certainly include disabled people. Aid and development workers may not see them or know about them, but they will be there and they are likely to be among the most vulnerable or marginalised people within the target beneficiary group.

Relief and development agencies need to learn more about Disability Equality and use it as a tool to redress current imbalances, to put an end to practices which discriminate (unwittingly or otherwise) against disabled people. This will lead to fuller, more effective compliance with their mandates and their humanitarian obligations. Oxfam itself is not without fault in this respect, although, like many others, it is now seeking to develop its understanding, analysis, and practice to address the reality of full inclusion for disabled people in its programmes and in their communities. In part this strategy is grounded in the experience gained from working with disabled people in Kosovo.

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## Notes

- 1 K. Davis, *Re-Defining the Disabled Underclass*, Union of the Physically Impaired Against Segregation.
- 2 Disabled Peoples' International (DPI) [www.dpi.org](http://www.dpi.org).
- 3 DFID Issues Paper, 'Disability, Poverty and Development', London, 2000.
- 4 Joshua Malinga, Chairperson of DPI, quoted in *Disability, Liberation, and Development* (written by Peter Coleridge, published by Oxfam, Oxford, 1993).
- 5 'Comprehensive Disability Policy Framework for Kosovo', Disability Task Force, Pristina, 2001.
- 6 Micheline Mason and Richard Reiser: *Disability Equality in the Classroom: A Human Rights Issue*, London: Disability Equality in Education, 1992.
- 7 A. Ratzka, Institute of Independent Living, 'A Brief Survey of Studies on Costs and Benefits of Non-handicapping Environments', 1994.
- 8 Adopted by the UN General Assembly in December 1993 and available at [www.un.org/ecosocdev/geninfo/dpi](http://www.un.org/ecosocdev/geninfo/dpi)