

2 What is ‘Disability Equality’?

Fundamental principles

The concept of Disability Equality is grounded in two fundamental principles.

Principle 1: Redefining disability according to the social model

Our understanding and interpretation of disability should be guided by the social model and recognise the three forms of discrimination – attitudinal, environmental, institutional – that prevent full inclusion of disabled citizens. (See Chapter 1.) Through applying this analysis, one comes to see that disabled people are handicapped by the barriers that society, and non-disabled members of that society, have erected around them. One gains a better understanding of disability – not as a medical condition, but as a product of the way in which society is organised, making insufficient allowance for the needs of all its members. Understanding the social model has been a turning point for many disabled people, and also for their allies.

Principle 2: Disability is a human-rights issue

Disability must also be understood within the context of human rights. The rights of disabled citizens are the same as those of non-disabled citizens. All people should have equal access to opportunity and services, as of right, be they women, older people, disabled people, or members of ethnic minorities. Many disabled people are isolated socially and/or physically, and learning about their human rights, including that most basic right to have some say and control over their own lives, has been the first step towards self-liberation.

The Universal Declaration of Human Rights (UDHR) has been signed by virtually every country in the world and underpins the philosophy and mission of many relief and development agencies. But disability has largely been ignored when human rights are under scrutiny. The physical and psychological discrimination that many disabled people suffer is not typically considered in the same manner as other violations of human rights. Most people associate human-rights abuse with politically or ethnically motivated killing, imprisonment, torture, and restrictions on freedom of movement and freedom of expression; they overlook the fact that every day disabled people are denied the right to express themselves, to make choices, and to obtain access to education, employment, and health care.

A rights-based approach to disability recognises that disabled people have the same rights as other citizens, although their entitlements may frequently be denied to them. The needs of disabled people are not different from those of other people. They have basic needs (for food, clean water, shelter, health care, education, and income); psycho-social needs (for friends, relationships, reproductive rights, equal access to services, and inclusion in the community); and political needs (to be able to organise, to associate freely, to be represented, and to have legal and voting rights). In addition, disabled people have fundamental needs in terms of communication and mobility that must first be addressed in order for them to be able to claim their other strategic rights as equal citizens. Meeting these practical needs is only a pre-condition, albeit a vital one, to enable disabled people to achieve inclusion in all other aspects of life.

Tools for change: Disability Equality training

Disability Equality training is the process of raising awareness of the causes and consequences of disability, and helping disabled people to claim their full and equal rights as citizens. Within the UK disability movement, Disability Equality has been promoted by disabled trainers as a tool to sensitise and mobilise disabled people to take action to lobby for rights and services. In Kosovo, Oxfam's Disability Equality training work was led by a staff member who as it happened was not disabled. There is no one way of carrying out Disability Equality training. Its aim is to bring about action that will lead to greater inclusion, equality, and rights for disabled people; this requires both action on the part of disabled people, and a change in attitude on the part of the rest of society. Thus both disabled people and their non-disabled allies are promoting and encouraging Disability Equality as a framework around which to construct an approach to disability that is based on the principle of equality of access to full services and rights as citizens.

Despite the deep poverty and discrimination experienced by many disabled people, Disability Equality training can be effective – because it begins by changing disabled people's perceptions of themselves. It focuses on what people *can* do, rather than what they cannot do, and it deals with feelings of powerlessness and the lack of self-confidence which might otherwise cause programmes to fail. Disability Equality training helps everyone to review their attitudes to disability, and their understanding of it, and to assess what changes they each might make towards overcoming the barriers that exclude disabled people from full participation in society. An approach based on a commitment to Disability Equality is equally valid for disabled and non-disabled trainees. It is about starting with what is possible, in terms of dismantling barriers to inclusion (be these in our own minds, or in the environment over which we have some influence). It helps disabled and non-disabled people to find practical, workable ways of putting principles into action. It identifies ways in which non-disabled people can support disabled people in their struggle for equal access and inclusion – not because this is a worthy thing to do, but because it is the right of all citizens to be included in society, on equal terms. These are some of the specific aims of the training:

- To empower disabled people.
- To encourage everyone to value the lives and contributions of *all* members of society.

- To create an enabling environment which gives each individual an equal opportunity to develop his or her potential and to participate and contribute in whatever way he or she chooses.
- To identify the particular needs of disabled people which must be met if they are to make the most of the opportunities open to them.
- To provide equal access to necessary resources.
- To encourage respect for differences and diversity, while celebrating our common humanity.
- To gain equal rights and responsibilities for disabled and non-disabled people, in law and in practice.

'Impairments can be endured, but the lack of human rights, the marginalisation and exclusion, the deprivation of equal opportunities and the institutional discrimination that disabled people face cannot be endured and can no longer be tolerated.'

(Maria Rantho, Deputy Chair, Disabled Peoples' International, speaking at the World Conference on Women, Beijing, 1995)

Myths and unconscious attitudes

As part of Oxfam's Disability Equality Training project in Kosovo, humanitarian-relief and development workers were encouraged to talk about disability, in order to uncover common assumptions, most based on misconceptions and ignorance, which helped to explain some of the inadequate programmatic responses to the situation of disabled people, and to validate the need for a Disability Equality approach. If NGOs are to meet the challenges posed by the exclusion of disabled people from society, and their invisibility in their own programmes, these attitudinal barriers must be identified, challenged, and changed.

Unconscious – or half-conscious – prejudice against disabled people was expressed in statements such as the following:

- *'We need to sort out the problems of "normal" people first.'*
- *'It's not cost-effective to include disabled people. ...Disability access is a luxury that we can't afford back home, let alone here.'*
- *'I feel sorry for them, but there aren't many disabled people here anyway, so it's not really an issue.'*
- *'It's not in our mandate – we don't "do" disability.'*
- *'We don't have the skills to work with disabled people.'*
- *'We should create a special programme for them.'*

Below we examine some of these misconceptions and offer a different perspective.

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

But disability *is* normal: disabled people are present in every community across the globe; it is just one expression of the diversity of the human race. Our perceptions of reality are distorted by social norms which keep disabled people out of the public arena, and by the narrow vision of beauty/perfection that is frequently presented in media images. The aid and development community works to counter conditions which would allow only for the survival of the fittest. It should recognise its obligation to work equally hard to improve the life chances and quality of life for disabled people.

‘It’s not cost-effective to include disabled people.’

Including disabled people is still all too frequently seen as something extra which happens only in an ideal world: it is a luxury, rather than an essential. The statement that ‘we only have enough money for the basics, so we can’t afford to include disabled people’ denies the reality that disabled people’s basic needs *are* the basics. While increasingly it is standard practice to assess the particular needs of specific population groups – women, men, children, older people – there is still little recognition that this applies equally to the needs of disabled people.

It does not necessarily cost a lot more to include disabled people in relief and development programmes. Billions of dollars of international aid were spent on reconstructing Bosnia after the civil war of the 1990s, but the opportunity to create once and for all an accessible built environment was not seized. Schools, hospitals, homes, and workplaces were rebuilt in a way that continues to exclude a significant part of the population. Accessibility is estimated to account for additional construction costs of between 0.1 and 3.0 per cent, yet the issue has not been tackled.

‘There aren’t many disabled people here anyway, so it’s not really an issue.’

One reason why the issue of disability is treated as something too specialised for the ordinary NGO is the misconception that the number of disabled people within the target population is insignificant. This myth arises because many disabled people are invisible. For example, if aid-agency staff see very few disabled refugees at camp registration or food-distribution points, they may assume that there are very few disabled people in the refugee population. In reality, disabled people may be hidden away, unable to reach these points; or they may never even have reached the camp. Disability affects not only the individual but also his or her family, who may also become a target for discrimination and face increased poverty and hardship.

In cases where the aid community is aware of disabled people among the beneficiary population, if the numbers of people are small or considered to be insignificant, this fact may be used to justify a view that inclusion of disabled people would not be cost-effective. This position is unjustifiable, since vulnerable religious groups or ethnic-minority groups probably are included. The key issue is not the numbers of people involved, but whether marginalised groups are recognised as such.

'We don't "do" disability.'

A further factor that prevents relief and development programmes reaching all those most in need is that disabled people have traditionally been regarded as a distinct target group, rather than being recognised as present within all wider target populations. Thus some agencies specialise in disability, and others do not. One consequence is that both donors and implementing agencies may assume that the needs of disabled people are adequately catered for if one agency is implementing a disability-specific project. But in reality only a small proportion of the disabled population may participate in and benefit from such a limited programme, while the needs of the majority go unmet.

Omitting a disability component from all programmes is akin to failing to address the needs of a group of people who account for approximately 10 per cent of the overall population. All agencies should include the needs of the disabled minority in their programming, in response to the needs expressed by disabled people and their organisations.

'We don't have the skills to work with disabled people.'

Working with disabled people is in many ways not significantly different from working with any other sector of the population. Many needs are the same; sometimes the approach to meeting them is different. Disabled people themselves are the best experts and can often suggest modifications which would make things work for them. Doing nothing is not acceptable. We may lack the answers ourselves, but all we have to do is to *ask the people concerned*. If disabled people are unable to suggest solutions, answers are usually not hard to find. Staff should inform themselves about likely problems and remedies as part of their advance preparation for field-work; organisations should address such needs for information as a routine part of staff-induction programmes.

For example, a public-health worker taking on a new assignment would routinely find out what type of public-health issues s/he is likely face. The same should be true for others whose role will almost automatically relate to people with disabilities. It should be standard practice that engineers are conversant with the kinds of modification that will facilitate physical access. Site planners should automatically consider how to design facilities in ways that will make all aspects of camp life accessible to disabled people without ghettoising them. These blueprints can of course be modified on the ground, to take account of local circumstances and individuals' resources and needs.

Becoming disability-aware is largely about changing attitudes: looking for solutions, not just seeing problems. Sometimes low-tech simple solutions have a major impact on life for disabled people in emergency situations. For example, simple bench seats with holes can be fitted to latrines; temporary guidelines made of rope can help newly displaced blind people to learn the route from tented accommodation to food-distribution points; water taps should be made accessible and usable by disabled people.

‘We should create a special programme for them.’

It is unrealistic to expect a single specialist intervention programme to address all the needs and rights of all disabled people. Many of these needs are anyway shared by other people and are not disability-specific, so they would be best addressed within the framework of the whole community. Just as relief and development agencies have been better able to address the needs of women by giving them particular attention, while ensuring that they have access to wider community services and structures (a process known as ‘gender mainstreaming’), the same is desirable for disabled and/or ageing people.

Piecemeal approaches, for example addressing only the nutritional needs of refugees in a camp without also considering how other needs (for water, sanitation, shelter, health care, representation, and resettlement) are to be met would be poor practice in any population. All too frequently, disability programmes focus on the mobility and rehabilitation needs of disabled people, without ensuring that they have access to the support structures and services that should address their other needs.

Care must be taken to avoid a situation where any programme that does specifically address the needs of disabled people inadvertently perpetuates the *status quo* of marginalisation and unequal access to resources. An unrepresentative approach is still very common in disability programmes, particularly in emergency contexts. Assessments and decisions may be made exclusively by medical and rehabilitation professionals. Non-disabled people may implement special programmes, giving assistance directly to family members: items to be passed on to the disabled person. This approach reinforces the common perception of disabled people as passive recipients of aid and care and as the objects, rather than the subjects, of rehabilitation programmes. Special or separate programmes tend to be based on the medical or charity models, as described earlier. As a result, proposed actions are often inappropriate or address needs that are not the most urgent for disabled people. This is inappropriate for organisations which endorse rights-based approaches based upon the principle of equality: for example, one of Oxfam’s core beliefs is that ‘The lives of all human beings are of equal value.’