

4 Guidelines for good practice

Even in the earliest stages of an emergency, agencies should plan for disability-specific provision at a later date. They can do this by including estimates based on overall numbers when drafting their proposals and budgets, and including the identification of disabled people in the registration process. Such steps provide a basis for on-going contact, and future consultation and service provision as the situation allows. Before the crisis in Kosovo, Oxfam had a dedicated staff member working there on disability issues, and a team who had undergone training in disability rights and gender rights and who were therefore disability-aware, committed to the core principles, and willing to voice them; this proved to be very important for the effectiveness of Oxfam's response in the crisis. But when the conflict escalated, it was necessary to ensure that disability issues were mainstreamed, and awareness of disability raised, throughout the programme and among everyone concerned. Donors, policy makers, and implementing staff – engineers, nutritionists, hygiene promoters, emergency programme managers, and so on – all need to develop a disability analysis, along with a clear perspective on gender: hence the publication of this manual.

Although much of the work in Kosovo took place in a context of crisis or protracted emergency, many of the principles and ways of working which led to the positive outcomes noted in the previous chapter are equally applicable to a more stable development context – as comparisons with other Oxfam programmes operating in distinctly different environments in Bangladesh, Uganda, Sierra Leone, and Bosnia have shown. It is therefore suggested that the following principles of good practice would in many circumstances lead to greater impact and more effective programming, to the benefit of disabled members of any target population.

A disability dimension in development

Disabled people are daily confronted by negative attitudes, pejorative terminology, and visible and invisible barriers which discourage their equal and active participation in the lives of their communities. They are seeking equal opportunities for inclusion, and the resources that are necessary to achieve this, as of right. Organisations mandated to deliver relief and support development must consider their responses to crisis and poverty from the perspective of disabled people and their needs, as well as those of other members of the community. The assumption that support for general populations will automatically benefit disabled people within them is false: disabled people do not have equal access to resources and opportunities, and specific measures are necessary to ensure their full inclusion and participation.

Agencies should incorporate disability into their current programmes as a high priority. Experience shows that it is vital to refer explicitly and distinctly to the needs of disabled people, and that failure to do so almost always results in their being overlooked. In the short term, therefore, it is important to develop a disability perspective that is applied deliberately and consciously to all aspects of relief and development work. In the long term it is desirable for disability to be included automatically in all elements of an organisation's work – in much the same way as situations are automatically analysed with reference to a poverty analysis and a gender analysis – by asking questions such as: *How can disabled people be included in this programme? What are their particular needs? How will they be affected by the programme? How can they be involved in decision-making?*

Many agencies now adopt a twin-track approach which allows for separate programmes to meet disabled people's specific needs in terms of communication, mobility, and information, as of right, but also attempts to include disabled people on an equal basis in all programme activities. For this, adequate resources are required.

Applying the social model of disability

Many disabled people are still unaware of their human rights and the social model of disability, since their own analysis has been shaped by the medical or charity models, and they have not been exposed to the ideas of the disability-rights movement. Raising awareness among disabled people themselves, and among agency staff, whether they work in development, conflict, or disasters, is essential. As a priority, disabled people should be supported to become activists, advocates, and facilitators. The lifelong discrimination that they have experienced and the resulting internalisation of their oppression mean that many disabled people lack the necessary self-confidence, information, or skills to do these things, but they have a wealth of ability and experience to draw on.

Aid and development agencies have an important role to play to support disabled people's struggle for equality by applying a social model of disability and principles of Disability Equality. These are the key challenges:

- Agencies and individuals need to become more aware of how their current practice, directly or by omission, contributes to discrimination against disabled people.
- Agencies and individuals need to engage actively with disabled people and their organisations, to learn from them, and to work together with them to overcome the barriers to equal participation.
- Agencies should adopt positive approaches to participation, and ultimately to recruitment, which allow disabled people to become colleagues and programme partners, not just beneficiaries.

Reviewing mandates and policies

Organisational mandates, policies, strategic plans, and programmes should be reviewed and revised, in the light of the UN Rules and the principles of disabled people's equal rights and need for participation. Such a review should be based on an understanding of Disability Equality, using input from experienced disabled people

– otherwise the quality of conclusions and decisions will be weak. Disability Equality training might therefore be the starting point for such a review, with further reviews of plans and programmes made possible once this has been accomplished. The process of inclusion, review, learning, and change does not have to be a top-down process; individual initiatives which respond to local needs can lead to change that is driven from the grassroots and they may become an effective catalyst for learning and broader application throughout an organisation. However, at some point such a policy shift must be clearly endorsed and fully supported by senior managers, who otherwise might block progress because of their lack of awareness and understanding.

Organisations should recognise disability as a key factor in their poverty analysis and methods of needs/assets assessment. Disability should be seen as a cross-cutting theme that underlies all relief and development work. Organisations should establish a disability policy which considers both relief and development issues, and covers all stages of programme funding and planning, implementation, monitoring, and evaluation, in order that disability is fully integrated into the project cycle. Oxfam addresses disability through its corporate policy on social diversity (see Appendix).

Disability Equality training

Disability-inclusive programmes can be given a kick start with short sessions of Disability Equality training for staff. In the long term it is desirable that all programme staff should share responsibility for the inclusion of disabled people in their work, but in practice in the short term the input of specialist disability staff has proved essential, providing specific support to programme staff and maintaining the profile and resources for inclusive work. In the early stages their role in influencing policy making and resource allocation has been fundamental to maintaining Disability Equality as a priority and encouraging non-specialist staff to create time to consider it. Ultimately a point should be reached where disability is integral to all programme work, and the inclusion of disabled people within beneficiary communities is automatic; then there would be no further need for designated staff.

Initial training should start with general Disability Equality issues and move on to focus on participants' specific areas of work. Disability awareness should be included in all briefings, debriefings, terms of reference, job descriptions, and person specifications for all staff (even those on short-term assignments). All staff directed to work in emergency contexts should be given Disability Equality training before leaving for the field, ideally as part of their induction or orientation when first hired. Wherever possible this training should be carried out by disabled people. Where the lack of suitably skilled disabled people or certain security situations make it impossible to use national trainers, expatriate staff may play a role in knowledge transfer and skill building. Headquarters-based training should use experienced Disability Equality trainers who have had some exposure to operating conditions and cultural differences in the countries where relief and development work is undertaken.

Consulting and involving disabled people

Disabled people have invaluable expertise and should be involved in all stages of programme planning, policy making, and implementation. Working together with non-disabled allies who are disability-aware, participants in even small projects can make an enormous impact on the lives of many disabled beneficiaries. Consultation must take place with representatives of disabled people's groups. This is vital, although it is important to remember that these groups may also reflect the unequal power relationships that exist in the broader community. If so, they may not necessarily represent all types of impairment, or poorer disabled people, or disabled women.

One of the more significant ways for disabled people to make positive changes in their lives is through peer support: sharing experience and gaining information through direct contact with other disabled people and their organisations, both locally and internationally. This should be encouraged and resourced. Organisational learning and exchange of experience should be supported, and media and advocacy strategies should be developed, to raise the issue of disability, and to support disabled people and their organisations in making their own voices heard, at local, national, and international levels. The UN International Day of Disabled People (3 December) is an annual opportunity for advocacy work.

Longer-term partnerships with local NGOs concerned with disability should be developed, and capacity-building programmes targeting local organisations and civil society should include disabled people and their organisations. The quality and effectiveness of disability-specific programmes (such as community-based rehabilitation, the distribution of orthopaedic equipment, and micro-enterprise and employment programmes) should be improved by prioritising the full and equal participation of disabled people. Since the 1970s, the disability movement and DPOs have been gathering strength, organising and taking action for political and systematic change. Disabled people are the leaders and active participants in this process; they have valuable experience and insights which can only improve the response of relief and development agencies.

Where disability programmes are implemented, the organisations running them rarely employ significant numbers of disabled staff. Disabled people should be offered employment opportunities within agencies, especially at levels of decision-making and influence. Opportunities in the Head Office are as important as those in Field Programmes: disability should not be seen as something that merely involves beneficiaries in the field. Disabled people should not be restricted to posts within disability programmes, although disabled staff with an understanding of a rights-based approach will make a great impact. Assumptions about a candidate's ability or inability should be avoided: the work experience and skills of disabled people are diverse, and disabled people, with appropriate arrangements for access and support, have become public-health specialists, interpreters, funding officers, project managers, evaluation officers, and more. Attracting and employing disabled staff will significantly improve the work of relief and development agencies, which will involve extra costs – but these should not be allowed to hinder recruitment. The resources that non-disabled staff need are already provided, and opportunities for disabled

people should not be prejudiced by failing to provide the resources that they need. Care must be taken to avoid inadvertently setting up disabled staff members to fail, by not providing the information or resources that they need to do their jobs.

After two years in Kosovo, relatively small changes that were made to increase the inclusion of disabled people brought about real progress in ensuring that there was a disability perspective in all programme work. Significantly, this initial progress was made without any additional resources. Subsequently budgets included disability costs where necessary, although it should be stressed that these costs do not represent the provision of something extra for disabled people: they merely represent the cost of meeting the same basic needs for disabled people that are met without question for others. Disability-related costs should be factored into budgets as a standard element; all agency premises worldwide should be accessible. Information and communication should be accessible for all staff, project partners, and beneficiaries.

Disability and humanitarian work in emergencies

The examples of the emergencies in Kosovo, Krajina, and Macedonia show that successful responses include the following elements:

- distribution of relief items based on local knowledge and beneficiaries' definition of their own needs;
- lobbying and advocacy work directed at, or undertaken in conjunction with, other INGOs and NGOs;
- building on development foundations, where the situation allows; and
- linking disability organisations with women's groups, to ensure that the needs of disabled women are not neglected. In the case of Kosovo, rural women's groups carried out disability-inclusive work themselves, using links formed through disability-rights training before the conflict.

The paramount need for physical protection

In emergencies a range of responses is required to meet the various needs of disabled people – as is the case with other population groups. Yet the major lesson for Oxfam in the Kosovo conflict was the fact that the primary need of disabled people is for protection. This fact was largely unaddressed throughout the conflict – except, within its limited means, by the KAPP. Reviewing the direction of the programme after nine months of conflict, both Oxfam and KAPP felt that disabled people had been failed in this respect. While protection is difficult to achieve, having access to information is crucial if disabled people are to make informed decisions and locate sources of help. The availability of better, accessible information might have made a difference to the fate of many disabled people. It was not common practice to use the State-controlled media to advise people about options and services available, but the Albanian-language radio and press could have been exploited for this purpose.

The need for advance planning

Emergency responses must be set firmly within a human-rights framework, demonstrating a commitment to ensuring equitable and inclusive service delivery.

Oxfam was fortunate in Kosovo: having already established partnerships with disability groups and women's groups, this could be achieved with relative ease, although there were times when partners found Oxfam slow and bureaucratic in responding to the emergency. Where such partnerships do not already exist and staff or implementing agencies are not disability-aware, equity and inclusivity will be much less easy to achieve. Agencies should plan in advance and integrate disability-awareness into the various sectors of their emergency response; when the humanitarian imperative is such that thousands of people may die if they are not provided with water quickly, it is not the moment to start deliberating for the first time ever about access for disabled people. Programmes in Lebanon, Bangladesh, and Kosovo have shown how the presence of a relatively well-organised disabled community, combined with disability-aware programme staff and partner organisations, improves emergency preparedness and can make an enormous difference when disaster strikes. The pre-existing relationship with KAPP made Oxfam aware from an early stage of the difficulties that disabled people were facing in the crisis. Preparedness work must assess the capacity of local organisations and the potential for external support.

Monitoring impact

Impact measurement should include disability issues within the overall framework of assessment, indicator setting, and monitoring. The *quality of participation* matters as much as the *quantity of beneficiaries*. It is necessary to consider the process of consultation, levels of satisfaction, and the reported benefits that accrue. The Kosovo programme demonstrated that there is no one right way to change individual and institutional attitudes. What works in one situation might fail in another.

The Kosovo experience demonstrated the need for significant changes at an organisational level, as well as at the individual programme level. When the war started and large numbers of expatriate staff were taken on, most of them did not have Disability Equality training, and it became a struggle for the programme to maintain an appropriate level of focus on disability issues and apply a disability analysis to the emergencies work. This unsatisfactory situation is unlikely to improve unless organisations like Oxfam instigate institutional change, reviewing their corporate policies and introducing training for staff.

Respecting the dignity of disabled people

Many disabled people who have led very independent lives before an emergency suddenly find themselves dependent on others during it. This additional trauma can undermine their self-respect and their coping strategies. Aid agencies can help by providing opportunities for disabled people to play an active role in the relief process, thereby re-establishing some control over their lives, and by providing them with the physical means to regain their independence. The Sphere Project – the Humanitarian Charter and Minimum Standards in Disaster Response – calls for *'equity throughout the distribution process, the equitable allocation of water, and toilet facilities that are accessible and easy to use by all sections of the population including physically and mentally disabled people'* (www.sphereproject.org).

Many of the items that disabled people need in emergencies are not different from other people's needs; but it is important to bear in mind that it can be harder for people with physical impairments to keep warm, due to lack of movement and poor circulation, so they may have increased need for warm clothing, blankets, firewood, etc. Exposed to crisis and trauma, people need to maintain their dignity and self-respect. In the absence of accessible toilet facilities, portable toilet chairs are cheap and simple pieces of equipment which can make an enormous difference to mobility-impaired disabled people. Pressure sores and urinary-tract infections can easily become fatal. It is essential that people with restricted mobility are able to change position, maintain hygiene standards, and be provided with catheters, barrier creams, and antiseptic creams. Enabling aids (hearing-aids and batteries, white sticks or the local equivalent, crutches, wheelchairs, portable toilet chairs, braille equipment) could be provided. While spectacles are already quite commonly provided in refugee camps to enable older people to participate in programme activities and daily life, it is less common for other aids to be recognised as essential.

Inter-agency co-operation

Agencies should address disability earlier than they currently do, given the existence of UN Conventions and Codes of Conduct which explicitly recognise and call for the inclusion of disabled people, and for their needs to be addressed on an equal basis with those of non-disabled people. As with all such texts, these conventions need to be applied in practice to make them effective, and personnel in the field must understand the issues in order to put the recommendations into practice. Raising disability issues at the interagency level in Kosovo helped to place them on the agenda at a time when agencies were busy responding generically and in so doing missing stark differences in needs and vulnerabilities. In later evaluations it became clear that in the early and middle stages of the conflict many disabled people were not reached and supported, and the structures that had been in place since the days before the conflict erupted were felt to be insufficient to overcome the problem. In reality, international agencies should have done more — and done it sooner. UNHCR, which is mandated to protect all refugees, should pay particular attention to the specific needs of disabled refugees, which in this case were not met.

The UNHCR Handbook for Emergencies recommends as good practice involving refugees in planning emergency responses, and promoting their self-reliance from the start. It also calls for the establishment of a system of refugee representation, which should be truly representative of all the various interests and sectors of the community and should be based on traditional leadership systems as far as possible — provided that they allow proper representation (for example, if the traditional leadership system excludes women, there should nevertheless be female representatives). These principles should be applied with respect to disabled refugees. There may be a need to provide information in a range of formats, to make it accessible to everyone. Camp committees should be encouraged to include disabled people — failing which, disabled people should be supported to organise themselves, to ensure that people are informed about and receive their relief entitlements.

Donor-driven agendas

Prioritisation of disability issues is also the responsibility of donors. Donor organisations, especially those who represent States signatories to the UN Standard Rules on the Equalisation of Opportunity for Disabled People, are well placed to encourage and fund projects which actively seek to include disabled people. Donors should consider the effectiveness of an applicant's Disability Equality policies and procedures; and, when analysing applications for funding, they should ask how the programme will affect disabled people within the target population. Budget lines to provide for Disability Equality should become standard. Donors can be most influential in the early stages, when fewer resources are available, and local and international NGOs are more receptive. They could therefore require a disability analysis, as many now incorporate a gender perspective, as a condition of all contracts. There is a particularly strong case for this to happen in the reconstruction phase after an emergency, since there is an opportunity for equal access facilities to be integrated from the very beginning, for example in the reconstruction of public buildings.

Lessons for disabled people's organisations

Experience in Kosovo has shown that the Disability Equality approach can be effective within disabled people's own organisations, especially in the following ways:

- in reaching out to the most marginalised and isolated disabled people;
- in achieving positive change in disabled people's lives;
- in helping the community's development;
- in being more effective in approaches to and collaboration with relief and development organisations;
- in developing an understanding of the rights and responsibilities of DPOs.

DPOs are encouraged from time to time to review their organisational mandate, policies, and practices in the light of the social model and Disability Equality. Organisations themselves need to guard against the risk of internalised oppression operating within their own structures. Does the organisation really represent the whole range of disabilities, the gender mix, and the socio-economic groups that it claims to represent? Accountability to the membership and access to transparent systems of decision making have proved important elements in building truly representative, community-based DPOs. Structures, membership lists, and programmes should be analysed, to identify the gender balance at all levels. Organisations should make conscious decisions about what to do to redress any imbalances between the sexes that may be found. Some associations have chosen in their early phases to focus separately on the needs and concerns of disabled women, and later to take positive action in an integrated way across the organisation.

Networking and developing contacts with other DPOs, both locally and internationally, can be vital for obtaining information, moral and technical support, links to donors, and experience. Other civil-rights movements may also provide useful examples, and DPOs are encouraged to share their knowledge and experience. DPOs should continue to lobby aid and development agencies for their support in building capacity and improving the impact of DPOs' own work. Through closer

collaboration, DPOs may help such agencies to turn rhetoric into reality, by developing and influencing their understanding and response to disability.

DPOs have successfully worked with the media to change the way in which disabled people are represented, thus ensuring that disabled people are represented in all their diversity and human complexity. It is not useful to replace one set of stereotypes for another. The Universal Declaration of Human Rights, the UN Standard Rules, and the social model of disability should be used as tools for analysis and programme design, public education and media campaigns, lobbying, and other actions. In order to achieve equality of opportunity for disabled people, it is vital to work with both local and national structures (related to education, employment, government) to bring about changes in attitudes, policies, budgets, and practical procedures, as well as changes in legislation.

Conclusions

The experience of Oxfam and its partners is that disabled people are discriminated against and excluded from full participation in society not only because of the physical limitations of their impairment, but principally by the attitudes of non-disabled people, and by the way in which society organises itself. This is the basis of the social model of disability, which recognises the equal rights of disabled people.

Oxfam and other agencies must consider whether their style of operating and their organisational culture explicitly or by omission exclude disabled people. Disability awareness requires action and commitment, as well as a willingness to experiment, to reflect, and learn from mistakes, and to do this in partnership and consultation with the people who will benefit. Any organisation that claims a human-rights basis for its work cannot really claim to uphold and respect those rights, or maintain its integrity, unless it is willing to adopt a disability analysis. As in other areas of development, if programmes are to be viable and effective, they will involve consulting beneficiaries; talking directly to beneficiaries; involving the community as well as direct beneficiaries; and making inputs and activities accessible. Working effectively to involve disabled people begins from these principles and does not necessarily require specialist input: respecting these basic good development principles in organisational practice is half the battle.

In addition, on the basis of the work conducted with disabled people's organisations in Kosovo, Disability Equality Training (DET) is suggested as one possible course of action. DET is relevant to both disabled and non-disabled people, although it should ideally be facilitated by trainers with personal experience of disability. The methods and outcomes presented in this manual are offered as a contribution to developing a way of working which will increase the awareness of disability and help to create an understanding of how and why disabled people are denied full participation and equal rights as citizens, and to develop realistic strategies to ensure their inclusion in society.

We conclude this section with the words of Myrvete, a disabled woman and activist from Kosovo: *'Just go for it. Never give up.'*

