

Introduction

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

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

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

Why this manual?

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

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

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

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

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

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

The geo-political context

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

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

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

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

Navigating this manual

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

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

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

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

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

Who can use this manual, and for what purpose?

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

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

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

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

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

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

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

A note on language

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

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

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

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

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

Hopes and fears

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

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

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

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

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

