

3 Working with disabled people's organisations

This chapter describes the work of a disabled people's organisation (DPO) in Kosovo. Although the details of the project are specific to the political and social context of Kosovo, the challenges confronting the DPO are typical of those encountered in many other countries, and its achievements show what can be done in an impoverished, conflict-ridden society, where disabled people and their concerns are not a priority on any official agenda.

The political context in Kosovo

Kosovo is a UN Protectorate, small, multi-ethnic, and predominantly rural, in southern Europe. It used to be an autonomous province within the Socialist Federal Republic of Yugoslavia, but in 1989 its political autonomy was removed, and direct rule from Belgrade, the Yugoslav capital, was imposed. A state of emergency was declared, and large numbers of security forces were deployed on a long-term basis. Kosovo had always been the poorest region of former Yugoslavia, and the crisis led to further impoverishment. The ethnic Albanian population, as part of their campaign of non-violent, mass non-compliance with the authorities in Belgrade, created parallel, unofficial systems of government, health services, and education. These functioned on meagre resources, and the impact of this long-term, low-key emergency on the poorest people of Kosovo – Albanian, Turk, Roma, and others – was enormously harmful. Many people in all ethnic groups faced hardship, abject material poverty, and an exhausting daily grind for survival. An estimated 80 per cent of the population became unemployed, one child in five was stunted by malnutrition, and the socio-economic situation resembled that of a less-developed country, rather than that of a province of a State on the continent of Europe. Feelings of fear, mistrust, and oppression dominated daily life, and there was no sense of security or confidence in the future. To live in Kosovo was to live in a state of permanent tension. In early 1998, the stresses finally erupted into open conflict between Serb and Albanian forces, and NATO intervention followed. In these circumstances, conditions for everyone, disabled and non-disabled people, deteriorated still further.

The situation of disabled people

It is estimated (by the Disability Task Force) that there are approximately 150,000 people with disabilities living in Kosovo. Before the civil war, most of them were physically and socially isolated. Having internalised their oppression, they had little opportunity or incentive to change the passive role to which they were assigned within their families and society. The social model was not well known as a tool with

which to analyse the reasons for their oppression; few informal or formal opportunities to meet other disabled people existed; it was hard to share experiences, learn from each other, and gain encouragement and motivation to change the situation.

Associations for disabled people existed, but they were specific to particular impairments and isolated from each other. Even where disabled people played major roles in these associations, their scope for decision-making and involvement was limited: a reflection of the top-down approach that was adopted by the government and prevalent in society in general. The organisations were usually male-dominated; where women did have positions of power, they frequently put all their energy (as did their male colleagues) into retaining and increasing their own status, rather than empowering others.

The position of carers

Like the disabled people for whom they cared, carers in Kosovo had few opportunities for peer support and organisation at the grassroots level. Mothers were (and still are) often blamed for producing a disabled child, provoking in them feelings of guilt, shame, and low self-esteem. Women's work in the family home is time-consuming and labour-intensive; the additional demands of looking after a disabled child often add a significant burden. While many carers love their disabled children and try to do the best for them, they may face criticism from family and community for doing so, branded as bad mothers who should invest all their energy, resources (including food), and attention in their 'healthy' children, rather than 'waste' them on a disabled child. The social pressures were (and still are) enormous.

In Kosovo a significant number of fathers took on the role of main carer. Anecdotal evidence suggests that this may be due in part to very high levels of unemployment since the start of the political crisis in 1989. In some families it was due to the perception that a child with a disability is a special or particularly difficult problem, for which a man should take the responsibility. In other families it was simply a reflection of the close relationship between fathers and their children. Both male and female carers reported feelings of isolation, of having to cope alone, without information, resources, or assistance.

The Kosovo Association of People with Paraplegia (KAPP)

The KAPP was formed in 1983. In common with other disability organisations in former Yugoslavia, it functioned as a parastatal organisation, in receipt of official funding for its running costs and activities. Unlike many others, it survived the period of pre-war crisis (1989–98) and managed to avoid schism and closure, retaining its original mixed ethnic membership. During this difficult period it remained functional to a limited extent, severely restricted by economic, social, and political constraints.

Between 1993 and 1994, international non-government organisations (INGOs) arrived in Kosovo and began assistance programmes, mainly distributions of food,

medicines, and winter items. KAPP was (and under its later name of Handikos still is) the only disabled people's organisation to have a network throughout Kosovo. Donors (who have included Handicap International – designated by the UN Mission in Kosovo as the international 'lead agency' on disability – and the Danish Council of Organisations of Disabled People, the World Health Organisation, and the Finnish Ministry of Foreign Affairs, as well as Oxfam) needed a local partner in order to avoid duplicating their efforts. Under the leadership of its original founder and President, Halit Ferizi, a wheelchair-user, KAPP became the main agent in the work of distributing supplies to disabled people.

Through the process of distributing aid, the KAPP became aware that its membership lists had become seriously outdated; an alarmingly high number of its members had died, very probably because of the lack of basic, essential, hygiene materials and medical assistance. Many others were seriously ill from causes that in more normal circumstances would have been avoidable. The KAPP came to realise that many people with types of impairment other than paraplegia, who now had no associations to represent them, were also in great need. It decided to strengthen its services, expanding its scope to include a cross-impairment membership, and restructuring its distribution mechanisms. It set about finding and re-registering former members and identifying other disabled people, regardless of their ethnicity and type of disability. Local sub-groups of the KAPP, known as Local Active Groups (LAGs), were established in approximately 20 places, covering both rural and urban populations. Many volunteers in the LAGs were medical staff employed by a local NGO, Mother Theresa Humanitarian Organisation (MT – unconnected other than by name and inspiration to Mother Theresa of Calcutta). MT had an established and growing network of 'health houses' throughout Kosovo, staffed by volunteer doctors, nurses, and medical technicians. Other LAG members were social workers, teachers, relatives or carers of disabled people, and (occasionally) disabled people themselves. The role of the LAGs was to identify and register disabled people in their community, establish their needs for medical and/or material assistance, and as far as possible provide for those needs, with their efforts co-ordinated through the central KAPP office. The KAPP's intention was to work towards a situation in which the LAGs would become independent from the KAPP; quite when and how this might happen depended both on the groups' own development and on external political considerations.

Oxfam's relationship with the KAPP

Oxfam's own relationship with KAPP dates from 1994, when it began work in Kosovo from its Belgrade base with distributions of winter clothing through local NGOs. The KAPP was one recipient organisation. Oxfam later opened an office in Pristina, the regional capital of Kosovo, and developed a programme which focused on building wells and latrines and the basic reconstruction of rural schools in one county, with a high level of involvement of the various ethnic communities. Complementary to this was the development of women's health-education courses in the county, and support for other rural women's organisations that were working to promote health, literacy, and girls' education.

Programme objectives

In a series of meetings with the President of the KAPP, Oxfam explained its broader mandate, beyond that of emergency-aid distribution. Staff raised the idea of using the principles of basic human rights as a starting point for effective work with disabled people. Both organisations agreed that *how* something is done, and the underlying philosophy, are as important as *what* is done, in terms of maximising the positive impact and sustainability of the project. Oxfam's key objectives in working with KAPP were as follows:

- to promote the social model of disability and to raise awareness of disability as a political and human-rights issue;
- to change attitudes to disability and introduce a Disability Equality perspective within the KAPP and LAGs, in order to make the groups' work (including distributions and home visits) more effective;
- to include disabled men and women in the groups, and support them to become active participants;
- to build a stronger, more representative organisation, which would have a more positive impact on its members' lives and on the broader community;
- to improve the self-esteem, status, and participation of disabled people – both men and women – inside and outside the organisation.

Both partners sought to promote understanding of what a disabled people's organisation could do to achieve real change, and to motivate people to take action to redress imbalances of power, both within the organisation and beyond it. A further aim of the group work was to offer support to family members and carers, to help to end the isolation that they experienced.

Development work with disabled people before the war

Work with individual groups

Oxfam began by developing relationships with four of the LAGs, to begin introducing the ideas and approach of Disability Equality, and to assess their relevance to the situation of disabled and non-disabled members of the KAPP. With each of the four groups, Oxfam staff began by attending group meetings and by accompanying members on home visits to disabled people and their families. Each group had its own particular composition and motivation; over time, the work with each group evolved differently, in response to the needs and personalities and interests of those involved. With some groups it was initially difficult to explain what Oxfam wanted to do – and why – in a meaningful way. In Kosovo most people associated humanitarian organisations (as relief and development organisations were collectively known) with aid-distribution and medical programmes. Although essential, these interventions frequently did not meet the medical or material needs of disabled people. They also led to the belief that an organisation which had nothing to distribute had nothing to offer.

In the context of the extreme material poverty of disabled people (and indeed of the general population) in Kosovo, words and ideas might have been seen as useless. Nonetheless, many programmes worldwide which seek to tackle poverty have discovered that responses to material needs, through income-generation or micro-enterprise projects, often fail unless the programme has first addressed the participants' lack of self-confidence and feelings of powerlessness. Unless people feel positive about themselves, they are unlikely to be able to bring about long-term changes in their lives. Campaigners for Disability Equality address this fact as a priority. In initial meetings with some groups, in order to be clear about their intentions, Oxfam staff apologised and admitted that they had mostly words to offer, because there was not much money for anything else. This explanation tended to be accepted by the disabled members of the groups. They were immediately interested enough at least to suspend scepticism, to listen and discuss. Some non-disabled people who had close personal relationships with disabled people in the groups were also very receptive and enthusiastic.

But there was a tension between tangible and intangible forms of aid, and it was reflected in an on-going debate within the KAPP about its own role. It pitted the organisation's President and other disabled members against others, mostly non-disabled people. At issue was whether LAG activists should visit disabled people only when there was something to distribute or they needed medical attention, or whether the role of the organisation was broader than this. Disabled people (and their allies) felt strongly that social interaction and other intangible forms of support were as important as the provision of aid and medical care, especially to people who were psychologically or geographically isolated. This notion was disputed, and sometimes even ridiculed, by some non-disabled LAG members. By providing information about the experiences of disabled people elsewhere, Oxfam staff were able to promote the broader role of the KAPP and LAGs, as well as highlighting the importance of peer support and role models in making positive changes to the lives of disabled people. They did this by arranging contacts and exchanges with DPOs elsewhere, and by providing the KAPP with disability-related materials in English and in translation, and with access to other sources of information over the Internet.

With one group the focus remained on attending group meetings and home visits, while trying to encourage links and information-sharing with the local women's group, which had activists in villages throughout the LAG catchment area. Another group's membership was in decline, but after a few months it re-formed, with a new membership which included many more disabled people. Then Oxfam concentrated on supporting them to set up a multi-activity children's community centre, run by disabled adults and relatives of disabled children. The centre's ethos was based on principles of human rights.

With the remaining two groups, the focus shifted to workshop-style activities and facilitated discussions, often held in the homes of activists or disabled people, for want of any other location. These sessions were very informal; each lasted for two to three hours, with activities which emphasised equal rights, models of disability, barriers to inclusion, concepts of independent living, and increased awareness of the experiences of people with varying types of impairments and disabilities, in order to support the development of a cross-impairment approach in the LAGs.

The opportunity for social interaction and making friends was also important, and there would be time for singing and chatting. On occasion, the effects of the political repression and crisis would somehow suddenly catch up with the participants: people would feel utterly worn down and unable to focus their attention on the topic under discussion. The groups were able to offer support to family members and carers who felt isolated. Oxfam wanted to encourage carers and other non-disabled members of the groups to think of disabled people in a different way: to look at the whole person, not just his or her impairment; to identify the positive things in the lives of disabled people, which were often unrecognised and buried under the burden of shame and tragedy, and to build from them. Disabled adult activists can be invaluable as role models and a source of information and support for disabled children and their parents, but this potential was often overlooked in the LAGs.

Regional workshops

The KAPP wanted to take the Disability Equality work out to reach more members in more LAGs; so, having tested some workshop materials, assessed their relevance to the first groups, and modified them as necessary, Oxfam staff agreed to hold more formal regional workshops with participants from each LAG within the six regions of Kosovo. The first regional workshop was designed with and co-facilitated by the President of the KAPP. Oxfam was concerned that most participants had had no previous exposure to participative workshop methods, nor any experience of dealing immediately with issues of Disability Equality. At subsequent workshops, two disabled LAG activists were included as co-facilitators, and a few people from the original groups were included as participants. Lessons from the initial work with groups were applied to later sessions, timings were adapted, and particular activities or issues were modified.

At each of the regional workshops there was demonstrable goodwill and openness on the part of most participants, who entered actively into participation and discussion. A small number of people who had been exposed to conventional styles of education felt threatened or alienated by the informal, interactive approach, and it was necessary to take this into account. They had been expecting the 'banking' style of learning, described by Paulo Freire in *Pedagogy of the Oppressed*, whereby a 'knowledgeable' teacher dispenses information to 'unknowledgeable' students, who are supposed to passively 'bank' or store the information that they acquire. On the whole, however, participants' reactions affirmed the reason for adopting an interactive approach: it was more enjoyable, and it helped people to relax, to participate actively, and to open up to learning.

Peer support

Sharing experience and gaining information through direct contact with other disabled people and their organisations, both locally and internationally, is a particularly significant way for disabled people to start making positive changes in their lives. Oxfam secured funding from various sources over a two-year period to support several such initiatives. A disabled woman was enabled to attend a short series of workshops on disabled women's issues in Belgrade, organised by the Autonomous Women's Centre. Another disabled woman attended the International

Conference on Self-Determined Living for Disabled Women, held in Germany in 1996. Disabled people were funded by Oxfam to visit Albania, to meet and learn about and exchange experiences with DPOs and the Oxfam Disability Unit there. And disabled people from Kosovo, together with disabled people from Belgrade, paid a visit to the Independent Living Centre in Dublin, Ireland. The Oxfam Regional Disability Adviser in Belgrade arranged a meeting between the KAPP and the President of Disabled Peoples' International (DPI), thus bringing the KAPP into contact with the global disability movement. KAPP representatives attended a regional disability conference for Oxfam staff and partner organisations. Links were established with Oxfam's programme and partners in Lebanon, and a visit was made there in August 1998.

The value of direct contact and peer support cannot be over-emphasised. People return from study visits with increased confidence and motivation, new ideas, a commitment to human rights, and renewed strength of purpose. Seeing experienced, successful organisations run by other disabled people can make a huge impact on those who are otherwise inclined to think that this would be impossible or impractical in their own situations. Sometimes the effects are immediately obvious, and sometimes they begin to emerge much later: it can take time to assimilate new experiences. Sometimes it will not be one single event, but a combination of several factors, that leads people to make positive changes. Contacts with groups in countries where similar cultural, economic, and/or political conditions prevail are obviously helpful, but the value of contacts with groups in the rest of the world, including more developed countries, should not be dismissed. As we have already argued, many of the factors that shape disabled people's experiences have little to do with the specifics of their cultural, political, or economic conditions, and more to do with globally negative attitudes, which result in the inequitable distribution of resources and power. Learning at first hand about the situation and the continuing struggle of disabled people in countries viewed as rich and stable can help to dispel myths and motivate people to take appropriate actions now.

Disability Equality Training of Trainers

Over an 18-month period, Oxfam's work with individual groups and the regional workshops and other activities had gone a considerable way towards creating a general understanding and acceptance of the relevance of Disability Equality principles to the KAPP's work and the lives of disabled people; and it had helped to build the confidence and abilities of certain individual members. The programme then moved on to the next stage: the Disability Equality Training of Trainers (DETOT) course. This was more structured training, which aimed to give LAG members the skills, knowledge, and attitudes to facilitate workshops about disability awareness themselves, and to raise awareness of the need for gender equality. In all, twenty LAG members completed the DETOT course and were able to share their learning with other LAG members and put it into practice in their everyday work and lives. The contents and methodology of the course form the bulk of this manual.

Work with women

For some disabled women in the LAGs, the discrimination they had faced – as women, as disabled people, and as disabled women – had left them feeling inadequate in social or group situations, believing that they had nothing to contribute, or too afraid to say anything in case it was not intelligent or correct. One woman apologised for not expressing herself clearly, saying she wasn't used to having the opportunity to express herself. Another woman could not remember ever having been asked for her opinion before. It was gradually possible to dismantle these barriers, by encouraging women to believe that what they had to say was valuable, interesting, and important (it truly was), by creating safe situations – like work in pairs or small groups – where it was easier to talk and gain confidence, and by not pushing women to speak when they felt uncomfortable.

Even after some time, when women (disabled and non-disabled) had begun to participate more broadly in the KAPP structures, their acceptance remained at times fairly tokenistic: often they would attend meetings but say virtually nothing. Or there would be an unspoken assumption that women could make a useful contribution only on issues that were specific to women. However, as some women gained strength and found their voice, their contribution did come to be recognised and valued; progress was slow but visible. Disabled men and women eventually began meeting to discuss personal matters and other issues, in private, without the involvement of non-disabled people.

Work with children

The KAPP organised a campaign of visits to disabled children and their families, with the aim of encouraging parents to take a 'whole child' approach and provide children with opportunities for play, social interaction, and education. This was followed up by a series of meetings with parents of disabled children, to encourage their involvement with the LAG. Seven community centres were set up throughout Kosovo, with disabled people and parents of disabled children organising activities and playing key co-ordination roles. Events for children in the community were organised: for example, picnics in the park, and a Christmas party in a café with a visit and gifts from Father Christmas, paid for by a local donor. To be out in the community having fun was a new experience for disabled children and their families, and it was important for parents to share their children's happiness and excitement. Such small things can have a big impact, changing families' perception of disability, improving relationships, and vastly improving disabled children's quality of life. Birthdays and traditional holidays were celebrated with parties in community centres, when disabled and non-disabled people danced until the small hours. Such banal, normal interactions played a great part in overcoming barriers between disabled and non-disabled people.

Using the media

An audiocassette of children's stories featuring disabled children was produced and broadcast on radio. For the first time, disabled children in Kosovo heard their own experiences reflected in stories, and were exposed to the discussion of ideas which they themselves might use in order to overcome some of the barriers that confronted them in society.

The public profile of disability was raised by the use of other media too. A magazine for rural women published poetry written by a disabled member of a LAG. She had never previously shown her writings to anyone, because her family had made her believe she was worthless. The magazine also published stories about disabled children and included images of disabled people. The same rural women's group worked with women from one of the LAGs to set up a literacy group for disabled and non-disabled women.

In Mitrovica, the local theatre contacted the LAG for advice on staging a play featuring a young woman who used a wheelchair. This was in itself without precedent: a wheelchair had never before been seen on stage. The non-disabled actress playing the role came to learn from disabled women about their experiences. However, there was uproar when the play ended with the disabled woman's husband killing her. Disabled women in the audience decided to write their own play, to counter this negative message and demonstrate to audiences that the suffering associated with disability is caused less by their impairments than by the attitudes of other people.

The KAPP and LAGs marked the International Day of Disabled People with round-table discussions in which disabled people could share their experiences and discuss their rights and their ideas for the future with members and leaders of the local community. Mixed groups of children sang songs and recited poems and produced an awareness-raising poster, portraying disabled people as integral members of society.

Education

Local Active Groups lobbied the authorities for access to mainstream education. They engaged in dialogue with families who resisted sending their disabled children to school, and with schools which were blocking willing parents from gaining a place for their disabled children.

A local English-language school provided a number of places on its courses, free of charge to LAG members who otherwise could not have afforded the course. This increased the visibility of disabled people within the community, encouraged interaction between disabled and non-disabled peers, and improved students' employment prospects. The opportunity to acquire language skills was particularly important, because English was fast becoming the only common language among Kosovo's various ethnic groups.

Institutional development

While all these initiatives were going on, Oxfam was helping the KAPP and the LAGs to build their own institutional capacity. This work took the following forms.

- Providing training in organisation management, including how to write funding proposals, how to manage financial accounts, and computer skills.
- Holding regular meetings with the KAPP President, to ensure inclusive, transparent decision-making between Oxfam and the KAPP in matters of fund-raising, planning, budgeting, and implementation.

- Developing the skills of a KAPP member who worked voluntarily in the Oxfam office, in order to gain experience in administration and finances that she could take back to the KAPP.
- Enabling the LAGs to make contact with other DPOs and thus to share experiences and support each other.

The KAPP successfully broadened its financial support-base, in order to reduce its dependency on any one donor. Gradually the KAPP and LAGs increased their skills and organisational capacity, which made them better prepared to act effectively in the escalating crisis.

Relief work with disabled people during the war

With the onset of war in early 1998, the KAPP remained active, despite very difficult operating conditions. Although by this stage it was fully committed to the social model of disability, strongly believing that service provision is the responsibility of the State, the KAPP recognised that in war-time there were gaps that had to be filled. It concentrated its energies on the following initiatives:

- Tracing disabled people displaced by the conflict.
- Helping displaced disabled people to find family members from whom they were separated.
- Helping displaced disabled people and their families to find suitable accommodation.
- Distributing emergency relief to displaced disabled people and their families (both general relief items and disability-specific items such as mobility aids and hygiene materials).
- Providing emotional support to disabled people who had been traumatised by the conflict.
- Continuing the work of raising awareness about the rights of disabled people.
- Continuing to run the seven community centres that were a focal point for LAGs and disabled people, as well as a resource for disabled children for physiotherapy, play, and education.

The KAPP worked through its extensive grassroots network to identify the problems of disabled people, and it lobbied Oxfam and other international NGOs for assistance. At that time many distributions (of food and other items) relied on people presenting themselves at warehouses in inaccessible locations, which was impossible for disabled people. As a result of KAPP's lobbying, Oxfam took the unusual step of providing sanitary items to 2500 disabled people who were at risk of serious health problems because this specific need was unmet.

Oxfam was able to make distributions of non-food items, such as clothes and shoes, through the networks of KAPP and rural women's groups. It was nevertheless difficult for the KAPP to reach its members: the front lines of the conflict were constantly moving, such that areas which were safe one day were not safe the next. It was hard to make plans, even where the location of members was known;

transport was difficult to secure, and the scattered locations of disabled people within the population meant that distribution was relatively expensive and difficult. Oxfam paid transport costs for the local distribution of supplies and delivered the goods as far as possible along the line, reducing the distances that the KAPP would then have to travel.

This type of distribution is time-consuming and labour-intensive, especially in a context of insecurity, but the KAPP was able to provide volunteer labour. Seventy per cent of these distributions were successful – a significant achievement, given all the difficulties, which reflects the pre-conflict strengths and skills within the KAPP. Individual local groups which were strong and active prior to the conflict were able to respond creatively and effectively during it; groups which had struggled prior to the emergency were less effective in the crisis. The joint efforts of KAPP and Oxfam enabled at least some of the needs of disabled people to be met, and their right to aid was not wholly neglected. In other aspects of its general response to the emergency, Oxfam attempted to meet the needs of disabled people: household-equipment kits included commodes, and accessible latrines were designed. In Macedonia an area within the refugee camps was established for disabled people, with accessible facilities and levelled ground. This type of work was carried out by the refugees themselves, both disabled and non-disabled.

Oxfam was also able to identify, with support from disability-aware field workers who were now in Macedonia following their own expulsion or flight, what problems would confront displaced disabled people when they returned to Kosovo. Oxfam then supported the KAPP to use its community centres as accommodation and support bases for disabled returnees, giving them the opportunity to assess what would be needed to enable them to return to their villages.

Before the emergency, Oxfam had supplied materials for the development of a disabled people's community centre in Pristina, and provided disability-awareness training in this and other centres established by the KAPP and Handicap International. Thus these centres had been helped to develop inclusive, rights-based principles and methods of working. During the emergency, the centres became important bases where displaced disabled people could find practical assistance and emotional support. Many disabled people learned about the work of the KAPP for the first time through these centres. For staff in the centres (disabled people and their non-disabled supporters), particular problems were caused by the lack of information about the current locations of disabled people and what had happened to them in the chaos of displacement. At the request of the staff, Oxfam funded transport to enable them to drive to areas where returnees had newly arrived, identify disabled people among the population, and link them into the available support networks. Through this process, more than one thousand displaced disabled people were identified and provided with assistance. Although these figures may seem small in relation to the scale of the emergency, they are significant in two ways. The effort invested by the KAPP and centre staff to produce these results was remarkable, and the identification process and follow-up support made a considerable impact on the lives of disabled people and their families, and in less immediately visible ways on the lives of the broader community.

Rehabilitation, reconstruction, and advocacy work after the war

Handikos (the new name for the KAPP) still works on the charitable and medical levels – not because it wants to, but because it has found itself obliged to do so. Despite its strong commitment to the social model, it recognises that some degree of service provision will be necessary for the next five to ten years. Its objective is to involve beneficiaries in the design of service provision, and this work is on-going.

The membership of Handikos has grown from fewer than 5000 members before the war to 18,000 now. However, Handikos staff and activists believe that there are still more disabled people who have not been reached yet, so they continue their activities of identification and registration. All who register by completing a questionnaire are considered members, even if they are not active, and they are given information on current projects so that they can choose whether or not to be involved. New questionnaires have been designed to include more information on people's abilities and the particular barriers that prevent their participation in society. Staff making home visits continue to inform disabled people about their rights and give them information about their entitlements. Some members have gone on to become trainers and have gained skills in setting up meetings, lobbying donors and authorities, and expressing their ideas.

The development of the Local Active Groups

Decisions within Handikos are made on the basis of needs expressed by its members and beneficiaries. The LAGs act as a medium for making grassroots voices heard, thus influencing the strategies and the future direction of Handikos.

There are now 25 LAG offices, each with three workers. They carry out field visits to obtain direct information on the situation of disabled people, and they are the first point of contact for new and existing members. All the field activities of Handikos are carried out through the LAGs, which are now organised into eight regions, each with a co-ordinator responsible for the running of the offices and community centres, writing proposals, and identifying training needs. (However, Handikos will shortly begin a programme of restructuring, and the number of staff will be reduced.) Most LAG staff are disabled, and overall approximately 60 per cent of the Handikos staff members are disabled. The groups vary greatly in the democratic nature of their decision making, which largely depends on the personalities involved.

Community centres

Handikos now runs ten community centres, where disabled children receive physiotherapy and group/play therapy. Before the war, everyone at the centres worked voluntarily, but now each centre has five paid staff members. Therapists have been trained, although they are not professionally qualified.

The centre at Peja, which serves 800 disabled people, illustrates the work of these institutions. It has the capacity to work with 60 children at a time, and the groups change every three months. There is good support for the centre from the local

community: the local municipality pays all the utility costs, and members of the community respond quickly to requests for help if there are problems with electricity or heating. This indication of support has prompted the centre to begin to look for local donors. Regular meetings are held with parents, to offer them advice: about the benefits of education; about new legislation to guarantee the rights of disabled people; about the dangers of over-protecting their children. The benefits of bringing parents together have been very noticeable: staff report that there has been a change in attitudes, and children are brought to the centre more often. Staff cite themselves as examples (all are disabled in some way) and teach parents to appreciate their children's abilities. When they first arrive at the centre with their children, parents tend to be seeking a cure; they need support to accept the fact that there will probably be no cure, and encouragement to believe that the situation will improve, and their children will be able to live fulfilled, independent lives. It is a slow process, but parents who gradually see their children benefiting from the centre's approach act as advocates of the social model to other members of the parents' group.

To further its work of raising awareness of Disability Equality in the wider community, the Peja centre has a good relationship with the two local radio stations and also has contact with the local TV station. Staff have held meetings with the three main political parties. They lobby local employers who discriminate against disabled people when recruiting workers, and head-teachers who have tried to block the registration of children in mainstream schools.

The centre is also home to a disabled women's group, which has 30–40 active members who meet weekly to discuss their needs and learn how to claim their rights. Their families tried to prevent the women from attending the meetings at first, but they have gradually become more supportive. The women learn handicrafts skills at the centre and teach each other to produce items for sale at a shop in town, which takes orders for their products. The income-generation groups give their members a degree of independence, although the amount of money earned is small. A local donor has provided materials for the craft work and helps with marketing. The women hope to open their own crafts shop in Peja, which would employ three field workers to sell products and look for outlets. They are confident that local wedding customs would guarantee a demand for their products.

The community centre also runs literacy courses for disabled women and girls, who have tended to be kept at home by their families. One 60-year-old participant from a village outside Peja wept when she joined a class, because it was the first time she had ever been to school. Computer courses have been very successful and have given the women employment skills.

Women's groups

Initially Handikos encouraged disabled women to join existing women's groups, but the hoped-for integration did not happen: the disabled women felt reluctant to participate in discussions with non-disabled members. It was therefore decided to offer them training in capacity-building skills in their own groups. With Oxfam's support, Handikos established sub-groups for disabled women within each LAG during 1999–2000. The groups are now managing themselves; they influence other

women's organisations on topics such as legal rights, and they visit officials of the United Nations Mission in Kosovo (UNMIK) to represent their own interests. Handikos has a shop in Mitrovica, selling handicrafts made by disabled women, and the shop is completely managed by the women themselves. However, the situation of the women's groups varies greatly from place to place, depending largely on the leadership skills of the members. Some are very strong, but others ceased to function after Oxfam funding came to an end in 2001, in accordance with a decision to cease the support of projects specifically and exclusively concerned with disability, in favour of incorporating awareness of the needs and potential of disabled people into the whole Oxfam programme in Kosovo.

Although the women's groups have made impressive progress in some respects, they face some serious challenges. For one thing, there does not appear to be a clear strategy for their future development; no other international donors seem interested in supporting this kind of project. For another, the activities of the groups are determined by cultural considerations: although on the surface Kosovo seems to be an open society, the lives of many women are still constrained, whether they are disabled or not. For example, although it is common for women to work, they are also responsible for maintaining the home, and in practice they cannot work over-time or travel overseas. Although in statistical terms women are well represented within Handikos, most of them are young and are likely to leave the organisation when they marry. Another problem is the considerable difference in levels of education between those born disabled and those who became disabled later: all the members of the Handikos executive were disabled as adults and have been educated in the regular school system. This means that at the decision-making levels of the organisation there is a preponderance of disabled women (and men) who lack first-hand experience of the problems of people who have been disabled all their lives.

Public education and media work

To a certain degree, the war changed public attitudes towards disabled people, forcing them to become visible when they were forced to flee with their families. Since the war, the disability movement has worked hard to keep its concerns in the public domain, and to raise awareness of the positive achievements of disabled people. A typical campaign slogan is '*Discover abilities to build opportunities*'. Television programmes, concerts, and sports events now feature disabled people. For example, in 2001 TV coverage of a basketball match between Kosovo and Albania was preceded by the live screening of a match involving the national wheelchair teams.

Influencing government policy

Handikos has made good progress in influencing the post-war policies of government (both UNMIK – the transitional administration – and municipal structures). It was a key member of the Disability Task Force, established by UNMIK in December 2000, with the primary task of developing a comprehensive strategy on disability for Kosovo, in line with UN Standard Rules on the Equalisation of Opportunities for People with Disabilities. The Task Force includes representatives of Handikos, other disability groups, and Handicap International. Its report, published in December 2001, presents a radical vision of a society in which

'all citizens, regardless of their diverse origins and abilities, are able to exercise their rights and responsibilities'. Its proposed strategy is based on the following principles:

- the right to self-representation
- the full integration of disability into all government programmes
- the need for sustainable funding.

The proposed policy objectives cover (among other matters) the State's obligations to prevent avoidable incidences of disability; to develop comprehensive health-care services for disabled people; to include disabled people in the planning and implementation of rehabilitation services; to create a barrier-free society; to develop an accessible system of public transport; to guarantee equal access for all to a single system of education 'that will cater for the needs of all learners within an inclusive environment'; to create conditions to broaden the range of employment options for disabled people; to ensure equitable access to goods, services, and facilities; and to ensure that disabled people are able to play a full part in political life.

The Task Force has proposed the establishment of a Disability Office in the Office of the Prime Minister, with the task of implementing the Comprehensive Disability Policy Framework at all levels of government in Kosovo. It is intended that the Task Force should be transformed into a Disability Council, to serve as a consultative, advisory, and monitoring structure on disability-related matters.

Livelihoods and education

Two particular areas of concern are livelihoods and education. Currently Handikos is the only organisation in Kosovo which systematically employs disabled people – a situation which needs to change, not only to increase opportunities but to counteract the idea that disability-related work is the only type of employment of which disabled people are capable. The general unemployment rate is 70 per cent – and the rate is higher still for disabled people. Proposals for the employment of disabled people have been made in the Comprehensive Disability Policy Framework, but progress will largely depend on political will and the economic situation of the country. Recruitment procedures do not automatically offer equal opportunities to disabled candidates, and physical accessibility is still a big problem in public buildings: although it is a legal requirement of reconstruction programmes (thanks to the influence of Handikos), it is not always ensured.

Handikos is working towards a fully integrated education system. In 2001 it ran literacy courses, funded and supported by Oxfam, to motivate disabled children and to make them and their parents aware of their abilities. Around 30 of the 200 participants now attend school and are completely integrated into the mainstream system. Through dialogue with teachers, individually and in seminars, Handikos also promotes the acceptance of disabled children in mainstream schools. More work still needs to be done with parents, to promote awareness of their children's abilities. Over-protection is common, and many parents choose to keep their children at home. Primary education is compulsory by law, but this requirement does not apply to disabled children. Illiteracy is a problem among disabled people, especially women and those living in rural areas, and (as noted above) there is a significant difference in

educational standards between those with congenital impairments and those who became disabled later in life.

The impact of international NGOs

Another challenge confronting Handikos is to recapture the spirit of solidarity and voluntarism that existed before the war. The presence of international donors and agencies has created inequality and unrealistic wages (a security guard employed by a foreign NGO may be paid five times more than a locally employed doctor, for example), and fewer people are now willing to work on a voluntary basis. But the international community will eventually withdraw from Kosovo, and it will be increasingly difficult for local NGOs like Handikos to obtain international funding.

Handikos has secure funding for 2002 and 2003, and will use the money to develop its sustainable social work. It would like to be able to work purely on the social model, handing responsibility for distributing medical supplies and services to the Department of Health. But the government is likely to take at least three–five years to develop this capacity, and it is doubtful whether international funding will remain for so long.

Mainstreaming disability issues within Oxfam

The Oxfam office in Pristina was totally inaccessible for anybody with mobility impairments when it was first established, and initially disability was considered to be an issue that was separate from the main programme. Despite its developing relationship with the KAPP, Oxfam at first made no attempt in its other projects to assess or meet the needs of disabled people within the beneficiary populations. In 1996 there began a slow and rather unfocused attempt (by Alison Harris) to encourage staff (and to a lesser extent Oxfam's project partners) in the main sectors of the programme to think about disability issues in relation to their work, and to develop a consistent approach which would integrate disabled people and their concerns into all aspects of Oxfam's activities in Kosovo.

Two one-day workshops were held for staff and partners (one addressing general Disability Equality issues, the second dealing with disability and gender). The lessons learned were reinforced through informal discussions and team meetings, and gradually there was a significant shift in the approach of Oxfam's management team in Kosovo. Disability issues were included in the strategic and programme-planning processes, and some of the reconstruction projects included the provision of ramps, handrails, and accessible toilets. Oxfam-supported women's groups planned and implemented basic strategies for including local disabled women in health-education work, literacy groups, and other activities. Other international NGOs which were engaged in reconstruction programmes were lobbied successfully to provide access for disabled people. The Oxfam office itself moved to accessible premises. Making the office accessible allowed more interactions, both formal and informal, among Oxfam staff (irrespective of their roles) and disabled people from KAPP. This helped to break through attitudinal barriers and contributed to a better understanding of disability. The benefit of this then began to percolate through to all of Oxfam's work in the region.