Case studies
Juma Juma, a self-employed shoemaker in Zanzibar Town, disabled by polio.
Introduction to Part Three

Part Three contains five case studies illustrating efforts by disabled people to work for constructive change in attitudes, policies, and practices in the field of disability and development. In each country the cultural, social, economic, political, and development background is very different. Zanzibar, a group of small islands off the coast of Tanzania, has a population of about 700,000 and an economy based largely on cloves; it is probably the poorest part of one of the poorest countries in the world. India, in vivid contrast, is a country of enormous complexity, with 850 million people and well over 1,000 languages. Zimbabwe reveals all the problems of a country struggling to emerge from a colonial past in a part of Africa racked by drought and enormous political change. Lebanon is on the road to putting itself back together after a protracted and bitter civil war, but the path is rocky. In the West Bank and Gaza Strip, major political conflict provides a backdrop of almost continuous emergency.

Despite the wide differences, there are strong similarities. In all examples the debate about development, whether in disability or any other field, is ultimately about empowerment: the struggle for personal dignity by people who have been disempowered through social inequality, injustice, violence, and the wearing down that comes from a life lived on the edge of survival. Disabled people are part of such a struggle, which in their case is sharpened and amplified by the fact of being disabled. But, as the case-study material will reveal, it is by no means a hopeless struggle. Even in the direst circumstances, creativity, personal growth, social cohesion, and constructive change are not just pipe dreams: they can be realities.
Attitudes towards disabled people in each country are similar, but reflect the different cultural and social backgrounds. Disability as a development issue in each of the countries is treated differently, both at government level and by non-governmental agencies. Taken together, the countries considered here illuminate, from different angles, the issues surrounding disability, empowerment, disempowerment, and development that have been set out in the first part of this book.

One should be careful of case studies: they are intended to illuminate the argument and the difficulties, not necessarily to provide models. I do not want to present these examples as models to be followed, but as slices of experience from which others can learn. Some of these efforts are clearly 'successful', in the sense that they achieve what they set out to do, which is for disabled people to influence attitudes and policy, and to take more control over their own lives. But they are fraught with the same pitfalls and difficulties as any other efforts in social mobilisation working for major change against deeply entrenched attitudes and interests. Perhaps one of the most important ways in which real empowerment and self-development can happen is when groups are given the space and the freedom to fail, and to learn from these failures on their own.
Zanzibar: Starting from scratch on CBR and social action

'The group has enlightened me: we give each other strength.'  
(Fatima Hassan)

Fact file

Population: The last census in 1988 showed a population of 640,000 (with an annual growth rate of 3 per cent) distributed between two main islands, Unguja and Pemba, and a number of other very small islands. Pemba is less developed than Unguja. The figures listed below are averaged for the two islands.

Religion: Islam

Culture: East African with Arab influence

Language: Swahili

Economy: 90 per cent of Zanzibar's income is derived from cloves, the price of which on the world market fluctuates wildly. Most of the cloves are grown on Pemba. Coconuts, coconut fibre, other spices, and tourism make up the rest. A recent addition on the east coast of both islands is seaweed farming for the Far Eastern market (used as both food and medicine). Small-plot cultivation, fishing, and boat building are the main elements of the subsistence economy.

Government: An Arab Sultanate under British protection which had ruled since 1830 was overthrown by the Afro-Shiraz Party in an armed revolution in 1964. Later in the same year, Zanzibar joined with the mainland to form the United Republic of Tanzania. In 1977 Afro-Shiraz and TANU formed
the single Tanzanian Party, Chama cha Mapindizi (CCM). The Zanzibar government is headed by a President who is also chairman of the Revolutionary Council. With the exception of foreign affairs, defence, communications, currency, and higher education, which is controlled from mainland Tanzania, Zanzibar has sovereign authority and its own ministries to implement domestic policies.

**Infant mortality rate:** Out of every 1,000 live births, 125 babies die before their first birthday and a further 210 die before their fifth birthday. The main causes of these high mortality rates are malaria and malnutrition.

**Average age of marriage:** 18.6 years. About half the women of Zanzibar give birth at an age when they are not physically mature enough for childbirth. The average age of marriage is lower in rural areas.

**Maternal mortality rate:** 300 per 100,000 births.

**Malnutrition of children under five:** Increased from 37 per cent in 1985 to 51 per cent in 1990. A main reason for this rise is the reduction in income of people in the rural areas, for whom food security is now a major issue.

**Immunisation rates** are high, and the incidence of diseases that are preventable by immunisation has fallen dramatically over the last few years. Malaria is the single biggest health problem.

**Khalfan: an interview**

Khalfan Khalfan is a wheelchair user whose legs were paralysed when he was a boy. In 1984 he founded UWZ — Umoja Walamavu Zanzibar (Association of Disabled People of Zanzibar) — which he still heads. It runs a programme of Community-Based Rehabilitation (CBR) in six villages on Unguja Island, and has fostered the establishment of groups of disabled people in villages throughout the two islands. It sees its main role as influencing the government to implement services for disabled people, educating disabled people about their rights, and raising awareness in the community on disability. It also runs skill-training programmes for adult disabled people. The staff and board of UWZ consist of both disabled and able-bodied people.

Q: So you went through school and eventually became a headmaster. How did you follow that course?
When I finished my schooling, I had to take an in-service teachers' training, because the normal teachers' training was not accessible. In my first school I began to take on more and more responsibilities and learned a lot about school management and administration; I was almost like an assistant headmaster, but I was just an ordinary teacher. Then ten years later, after I had proved my capability in school and management and administration, the ministry promoted me and made me an assistant headmaster. Two years later they made me a full headmaster.

Q: Why did you stop teaching and move into disability work?

Basically I wanted to teach in another way — because, you know, I am still teaching, but I am not teaching students in the classroom! So now I am teaching the population on disability issues. I thought if I remained as a teacher and did the disability work, I wouldn't manage either properly.

Q: What was it that convinced you that there was a need to work in disability?

Up to 1981 I had no idea about the disability movement. I was just Khalfan, disabled, and I did not have contact with any other

Khalfan Khalfan, founder of UWZ, with Zwena, a CBR worker, visiting the home of a disabled child in the village of Kilimani Dole, Unguja.
disabled people or with disabled organisations on the Tanzanian mainland. In fact I did not know that disabled people had organisations. So it was by sheer chance when I corresponded with one organisation in London requesting a wheelchair and they told me they don't provide wheelchairs for foreigners, only for people in Britain, but they gave me the address of DPI (Disabled People's International), which was just formed at that time. They suggested I contact them, and they told me DPI were having a meeting in Singapore.

So I wrote to DPI — in fact not requesting a wheelchair, but asking to participate in this meeting. I told them I didn't have any organisation in Zanzibar, I was disabled and did not have the money to travel to Singapore, but I would be interested to come as an observer. DPI sent me a ticket and I went.

There in Singapore I came to learn about disability. For the first time I met other disabled people — so many disabled people coming together from different parts of the world, with very strong organisations and some weak ones too. I was focusing all the time, asking a lot of questions of disabled people. So I went home and thought, 'Now there is a need to organise the disabled people in Zanzibar so that they will be able to achieve some of their rights.'

Q: But if you had not met other disabled people, would you have been aware of a general problem in Zanzibar as far as disabled people were concerned?

No, I was not aware. I was just aware of my own problem.

Q: And how would you identify your own problem?

I had a lot of problems. I suffered negative attitudes, even with some of my employers. For example, when I was just about to travel to pursue a diploma course in educational administration and management in London, at the last minute my employer said, 'No, we don't allow sick people to travel.' He used that term in fact! And I was very angry about that. I wrote a strong letter to the Ministry, saying that if I was sick then I was not fit to teach; so I would have to resign if I was not fit, and leave the job. And they wrote back and apologised and all that. But I didn't go to London.

Then there was the problem of accessibility; it used to frustrate me a lot, not being able to go places I wanted, like the cinema. And then sometimes you meet people who insist on treating you as incapable
because you are in a wheelchair. That was true even among my employers.

Q: So on coming back from Singapore, you were very strongly motivated to do something about the situation. How did you start working on it?

I wrote a report to the government about the Singapore conference, and then I made some suggestions. One suggestion was that I needed to be supported by the government to move around and talk to disabled people, to give them information about what I had learnt in Singapore.

The second suggestion was that we be allowed to form an association. But then it was not that easy. The government did not accept it immediately. It was being delayed and delayed, from 1981.

Q: What was their objection?

At that time ... maybe they were either ignorant or a little bit suspicious: I might be dealing with a political movement or something. The other thing is that some of the government officials came to the point of saying, 'Why do you want a separate organisation? What do you want, Khalfan? If the disabled people have a problem, they can go to the Social Welfare Department.'

Q: So their attitude was basically: 'The government will provide; you don't need to organise your own provision.'

That's right. That was their attitude. That went on up to 1984, when there was a change of leadership, and we got it through with the new leadership.

Q: Was that their attitude to any kind of non-governmental organisation being formed in Zanzibar?

Well, in fact we were the first one, so after ours there came others, but before then there were no NGOs in Zanzibar.

Q: What provision was there for disabled people before you formed the association?

There was very little. A very few people were provided with wheelchairs, but that was about all. There was a little bit of physiotherapy, and some provision of callipers and crutches, but it was very limited.
Q: So you finally managed to form your association in 1984. What were your immediate goals?

Our first main objective was to mobilise all disabled people under the umbrella of this organisation, and then to sensitise the disabled people about their rights and the obligations of their society.

Q: So it was educating disabled people, rather than the able-bodied community.

Yes, at first, because the first step is to have members who accept your organisation. So we thought the first thing is, we have to educate the disabled people to know their rights.

Q: How did you reach them?

We used the structure of the party (CCM), because after forming the organisation we were registered and recognised officially. After that recognition we used the social welfare department of the party, and they were the ones who were travelling together to different villages in the two islands asking disabled people and the parents of disabled children to come together at local party branches. I talked with my members to discuss the issues of the rights of disabled people, education, the importance of having an organisation, and all these sorts of things.

Q: And did you find that people in the rural areas understood what you were talking about?

Not very much, because of the situation they were in. Whenever anyone appears in rural areas, the people normally think of charity; their first reaction is that with this organisation we might get some money or clothes or food, so at first many people did not really understand the objective of the organisation.

Q: But don’t you think that people in a rural area are perhaps as well integrated into village life as they are ever likely to be, and therefore there isn’t much that a central organisation can do to improve things?

Well, they are integrated, but they are not involved. I mean they may live in the community and be accepted by it, but they are not involved in its decision-making and in participating in general activities. So it is not full integration; they are, or were, still isolated in significant ways.
Q: So they were kept out of the decision-making by their disabilities.

Yes, and because of society's negative attitude. And they thought that the community could make decisions on their behalf, including about their rights.

Q: What kinds of right would a village person demand which they don't already have?

First, the village set-up in Zanzibar is very different to the set-up on the Tanzanian mainland and Kenya. There is very little difference between the village and the town in Zanzibar; village people always have a very strong relationship with people in the town. That's the pattern of our life. So they've got their rights, for example their right to education, because eleven years of education are compulsory in Zanzibar. But most disabled people do not enjoy this right. That's one very important area.

Then there is rehabilitation. It is also a right, but most disabled people in rural areas don't have the facilities for rehabilitation. They cannot afford to attend a physiotherapy unit in the town. They do not have access to callipers and so on. The only people who have access to these things are those who live very close to the town, and even then it's very few of those.

But even employment is an issue in rural areas. Two blind people told me the other day that they wanted to work in a coconut collective, but the landlord said, 'No, you can take ten shillings and go!' So employment is a major issue and a right.

Q: So it was the need for rehabilitation which led to your CBR programme eventually.

Exactly.

Q: How can it be applied more widely? At the moment you are concentrating on six villages which are quite close to the town.

In fact we want the government to implement the rest, because we as an NGO are a small organisation in Zanzibar; we have just shown the way.

Q: So you are putting the ball back in the government's court.

Yes. It is the responsibility of the government to do Community-
Based Rehabilitation. We as an organisation can work with them, show them the experience we have. They can use our workers for training other workers, and so on. But we as an organisation do not see it is our role to take on CBR over the entire country, because we cannot manage to do that; and besides, it is the government's responsibility. That is why we don't want to move into other areas. The government has asked us several times to do that, but we feel it is their responsibility.

Our organisation is a pressure group, and it has been able to influence the Minister of Education to adopt a policy of special education, and the minister has already started sending teachers to be trained to teach the blind and the deaf. They now have a few classes in Zanzibar which did not exist before. So now at least we have a few classes for the blind and for the mentally retarded, and we hope that each year the ministry will establish more and more units. So this is the impact of our organisation on the situation of disabled people. The Minister of Health has collaborated with the Prime Minister's office to set up a special task force to work on a policy for rehabilitation.

Q: So pressure to provide services is a very important part of your work.
Yes, definitely. We are also working closely with government offices in different ways: whenever disability issues arise in any of the ministries, they use us as consultants, and we are happy to do that. For example in special education we are not experts, but we know people who are, and we provide these contacts to the government. Recently I was in Oslo and visited an institute for special education, where they said they would take two people from Zanzibar on their next course.

A model of co-operation
How does action for change start? The development of UWZ is a classic story of a personal learning experience leading to effective action and social change. Khalfan had proven ability and an excellent reputation as a headmaster, and his accidental discovery of the disability movement fired his enthusiasm to start work in disability in a situation where almost nothing was being done. The story from then on illustrates insight, diplomacy, ability to inspire and mobilise others, organisational skills, and political judgement. Zanzibar has been lucky to have someone with these qualities
available and exceptionally well-placed to take such an initiative. Zanzibar is also lucky, despite its severe poverty, to be a small, homogeneous, and close-knit community where many people now holding government office have passed through Khalfan’s hands as pupils when he was a headmaster. There could hardly be a more auspicious basis for starting constructive work in disability.

These are very considerable advantages. There are many valuable lessons to be read in the Zanzibar example which could be remembered elsewhere:

• the vital importance of networking (in this case by DPI) on a global scale, especially for an isolated population like that of Zanzibar;

• persistence in the face of bureaucratic obstacles;

• using all available means to reach people, including the government structure itself, and not trying to set up a separate monolithic structure;

• winning the government over and working constructively with it instead of alienating it;

• keeping in focus the need to sensitise disabled people themselves as the first objective of the new organisation;

• recognising the limitations of an NGO like UWZ, and insisting that the ultimate responsibility for full service delivery lies with the government: the role of UWZ is to show the way and then provide advice, expertise, and pressure to start new services.

The result is a model of co-operation that would be the envy of most NGOs in the South. That is not to say that all the battles have been won; but given that there was almost nothing before UWZ came along, the achievements are very significant. UWZ has succeeded in a few years in both being an advocate for the needs and rights of disabled people and setting up a model for a basic rehabilitation service.

Making a start on community based rehabilitation

The UWZ CBR programme raises the dilemmas familiar in any rural rehabilitation effort dealing with a scattered population. Although Zanzibar is small by African and Indian standards, the roads are very poor and public transport almost non-existent in many places;
private cars are an extreme rarity, and so are taxis; bicycles are the most common form of personal transport, but are used almost exclusively by men; it is not uncommon to find women who have never been to Zanzibar town in their lives, and whose world is entirely bounded by their house and their village. Unlike the Tanzanian mainland, where women do most of the cultivation work on the family plot, in Zanzibar it is the men who do the bulk of the agricultural work, aided by women at peak times like harvest. But the work of, for example, drying cloves, which is done at home, tends to fall to women.

Zanzibar is a Muslim society, and while that does not place Zanzibari women in purdah or lesser kinds of seclusion found in some parts of the Middle East, it does restrict their social mobility more than their sisters on the mainland. For urban women the problem of mobility is less severe, but still significant.

Saada is 15 and was born with severe cerebral palsy. She is one of eight children: seven girls and one boy. Her father is a shopkeeper in Zanzibar town. Her mother describes her life:

I knew that she was not normal, but I did not discover what was wrong until five years after her birth. Saada was given a little physiotherapy at the hospital, but it didn’t make much difference; she remained completely dependent, unable to dress, toilet herself, or even sit up from a lying position.

Then when she was 12, the UWZ CBR programme started and Zwena, one of the staff, began visiting us at home once a week. We have been working together to free up Saada’s stiff muscles so that she can sit; we have also worked on toilet training. Now she can sit up from a lying position; it has made a lot of difference: she is much happier and takes more interest in what is going on around her.

In relation to my other children, I feel that Saada is intelligent and special: she is a happy and deeply affectionate child, and she has a strong sense of humour. Her brothers and sisters try to include her as much as possible. One sister in particular takes good care of her: she dresses her and toilets her before going off to school.

Now I am pregnant again. If I knew that my next child was going to be like Saada, what would I feel about that? I would prefer a normal child, but whatever happens is God’s will. I love Saada, we all love her, but I feel tied.
After three years of weekly physiotherapy sessions with her mother and CBR worker Zwena (r.), Saada, a severely disabled child, is much happier and takes more interest in the world around her.

Most Zanzibari mothers of disabled children find themselves similarly isolated. The implications are obvious: if the mothers are stuck at home, so are their children. The greatest need is not so much to provide rehabilitation at home, even though that is clearly necessary, but to create the opportunities and possibilities for mothers and their children to meet, socialise, and learn from each other. For this reason, it is unsatisfactory to regard a CBR programme as merely a system of home visits: it needs to be used as a means of breaking the isolation of families with severely disabled children like Saada. That is why UWZ set up a system of playgroups as an essential part of its CBR programme. Contact with other mothers through the CBR playgroup organised by UWZ gives Saada’s mother essential support: she does not feel alone.

The task of the CBR rehabilitation staff, as they see it, is to remove barriers: freeing up children, despite their disability, to realise their full potential. Ramadhani, now 13, is the sixth of seven children; he and his family live in the village of Kilimani Dole on the main island, Unguja. He was a year and two months old, just starting to walk, when he was struck by a high fever. His mother describes what happened:
When he came out of the fever, I found he could not use his limbs. I did not know what disease it was; all I knew was that Ramadhani was paralysed. I managed to get him to hospital, where I learned that it was polio. They said there wasn’t much that could be done for him. So I took him to traditional healers and they used local oil and massaged him to straighten out his limbs, because he was very stiff. They managed to loosen him up a little and he recovered the use of his arms, though they are still weak.

His father farms a family plot of about two and half acres growing cassava, maize, and bananas. They consume nearly all they produce, selling occasional surpluses to find the money for essentials like clothes, tea, sugar, rice, and (on rare occasions) meat or fish. Ramadhani does not go to school, although he would very much like to:

I am interested in machines and things that work; I want to be an electrician. Three of my brothers go to the school — it’s about a quarter of a mile away; there are two shifts, one in the morning and another in the afternoon. But I can only crawl and cannot get there. I

Ramadhani: ‘As soon as I can walk, I can go to school.’
don’t think a wheelchair would be much use: there is no road, and the ground is very rough. My mother says that as soon as I can walk, I can go.

For the past year he has been visited by Hasan Khamis, one of the UWZ CBR staff, who has been working with him and his parents to prepare his legs for callipers. He has been wearing corrective plaster-casts and learning to use crutches. He already feels more independent, though he finds the crutches quite a struggle, because his arms are weak.

For Ramadhani, school stands as the major incentive, a goal driving him to struggle with crutches and callipers. Clearly bright and determined, he will probably make it. Are there shades of the Peto Institute here, of ‘normalisation’ against the best interests of the individual disabled person? Perhaps. But the poverty and harshness of his immediate environment are the reality. The choices open to Ramadhani are to struggle or wither.

In my interview with Ramadhani’s family, it was suggested that perhaps his brothers and sisters could take him to school in a small handcart, which they already use to involve him in play away from the village. His parents rejected this, because they wanted him to be as independent as possible; if the crutches and callipers proved too much, the cart might be a backstop, but they felt that he should have the incentive of unaided mobility first.

Removing barriers at the individual level is the main purpose of CBR. For Ramadhani it is happening. For Saada’s mother the barrier of her isolation and feeling of aloneness has been removed (at least in part) by the contacts she makes through the playgroup scheme.

Village disability groups: discovering solidarity

The UWZ CBR programme, which deals only with the rehabilitation of children, runs in six villages within easy reach of Zanzibar town, as a pilot project, in order to demonstrate the principle to the government. But what of the adult disabled people throughout the islands? As with the rehabilitation of children, breaking the isolation of disabled people is the primary objective of UWZ: in both Unguja and Pemba islands, UWZ has a network of members, who are recruited by district secretaries.

Mwantatu Mabaraka contracted polio as an adult, and her right leg is affected. She is District Secretary for UWZ, based on the village of Bungi (population about 2,000), but covering adjacent
villages too. Her job is to make people aware of the organisation in
the villages and to mediate between the UWZ office in Zanzibar and
the members.

I am also a member of the group in Bungi itself, which I started two
years ago. We have 18 members, both men and women, who have a
range of disabilities including hearing, mobility, and learning
impairments. I feel that UWZ has achieved a real change of attitude in
the villages where I work. There is a difference in the way disabled
people are treated in the villages. What has made the difference? The
main influence, I think, is that the chairperson, Khalfan, who is himself
in a wheelchair and widely respected, passes through here and meets
disabled people. Also government representatives come and talk to
them. So they feel they are recognised, and other people change their
behaviour towards them too as a result of this recognition. Our group
in Bungi has recently opened a tea shop which sells basic necessities.

What does integration mean within a small, close-knit village
community in Zanzibar? Khalfan made the point above that while
disabled village people may be accepted by their communities, they
are not involved in decision-making in the same way that other
people are. They need recognition as well as integration.

Through interviews with many people in these disability groups
in Zanzibari villages, two points repeatedly surfaced: the strength
which they gained from meeting each other, and their need for
better economic opportunities. Some are finding it through co-
operation with each other, and some have joined forces with able-
bodied people. Prospects for such cooperation in the town are
considerably better than in villages. Haji Maulidi Haji is 27 and
lives in Zanzibar town.

I had polio as a child and I can walk only with difficulty. I use a hand-
powered tricycle to go any distance. When I was 20 I set up a bicycle
repair shop with a friend who is not disabled. We can repair about ten
bicycles a day and earn 7,000 shillings a week between us [about
£35.00, a very decent wage by Zanzibar standards]. I am not married;
I live with my brother; my partner is married with several children. I
feel that an enterprise where a disabled person works with a non-
disabled person is the best arrangement. I would like to expand this
workshop and employ both disabled and able-bodied people.

Much of the effort of UWZ with village disability groups goes into
finding and creating opportunities for improving earning power. In
February 1991, in Makunduchi, a village on the east coast of Unguja island, some disabled women formed their own group. The ten members have a range of disabilities including polio, visual impairment, and deafness. The group mobilised initially around an income-generating project based on coconut-fibre products: rope making, matting, and brooms. Fatima Hassan is a member; she had polio as a child, which left her with a weakened arm and a deformed leg. She has three children who are now more or less grown up; her husband divorced her a few years ago.

Why did we form a group? The UWZ worker talked to us and explained what was happening in other villages, and it seemed a good idea. Disabled women especially are in a very difficult situation. Take me: I'm both disabled and divorced, and my children, who are almost grown up, do not give me much help, even though they depend on me financially. I was pretty desperate.

Since forming the group, my life has changed. It has helped me in so many ways, but mainly in providing a support in my difficult situation. The group has enlightened me. It's not only about production: we give each other strength and also practical help in many little ways. We meet once a week on Thursdays. It's women only. Why? It would not be possible to have a mixed group of men and women. If we had men, they would dominate. We would rather stay as just women.
We started this rope making project. It's hard work and doesn't bring much: so far 2,500 shillings for the whole group [about £12.00], but we hope we can earn more than that. We start with the raw coconut husks and bury them under the sand by the sea and leave them there for six months; that makes them easier to work. Then we beat them with heavy sticks until they become pliable, and then we start making the rope. The problem comes in the selling; we sell the rope to merchants in the village who take it to the town. Who controls the prices? The merchants, of course. The whole process of selling and buying works against us.

So if they could sell directly, they would earn more. Why don't they take the rope to town themselves, and cut out the merchants?

It would be impossible. We do not have that kind of mobility, not in this village. We need to find someone we can trust, but we don't trust the merchants. Look, I'm not complaining that much: this group is the best thing that ever happened to me. If I am at home inside all alone, that itself is a disability. Joining the group is a kind of liberation. We have so many ideas we can share with each other. I hope we can solve the marketing problem.

The situation for disabled women is difficult everywhere: they live under the double disadvantage of sexism and 'handicapism'. The testimony of women like Fatima Hassan provides a small insight into the limitations imposed not just by their disability but by a society which regards it as inappropriate for women even to travel to the town on their own. But the groups formed around UWZ, still young, are gradually opening up new horizons for Fatima and others like her, and a vision of a life where they can begin to experience something of what it means to be empowered.
Zimbabwe: forming a disability movement

'We do not speak about politics; we speak about survival.'
(Simon Tevera)

Fact file

Population: 9.7 million (1991 estimate)
Main ethnic groups: Shona 77%, Ndebele 18%, others 5%
Religion: Traditional animist 60%, Christian 40%
Population growth rate: 3.5% p.a. (estimate)
Urban population: 27% (1989)
Adult literacy: 81% of men, 67% of women (1985)
Life expectancy: 64 (1989)
Infant mortality: 49 per 1,000 live births (1988)
Gross domestic product: £2,605 million (1990)
Average income: £200 per capita (1991)

Background

The disability movement in Zimbabwe is one of the most vigorous in Africa. Why?

Tourist brochures describe Zimbabwe as a land of contrasts; a recent Oxfam publication\(^1\) describes it as a land divided. But the country strikes the first-time visitor today as a model of energy, cohesion, and unity in a divided continent and a fragmented world. Most of the infrastructure is impressive, the roads are superb, the
telephones work, the cities are whistle-clean, and there is an infectious enthusiasm for life among ordinary people that seems uniquely Zimbabwean. Zimbabwean music throbs with a powerful soul. The prolific and gifted Zimbabwean sculptors working in stone reveal a deep seam of creative energy reaching far back into an ancient culture — a culture that is embodied most dramatically in the amazing ruins of Great Zimbabwe, a city created by the Shona people between the thirteenth and fifteenth centuries, whose beautifully engineered dry-stone walls are one of the wonders of Africa.

Standing in a street in present-day Harare, with its broad, tree-lined avenues, splashing fountains, well-kept parks and public gardens, smart buildings, and people in neat office clothes, it is hard to reconcile this image of Africa with the all-too familiar television images of famine, war, and destitution.

But whether one speaks of a land of contrasts or a land divided, the tourist brochures and the Oxfam publication are right: one should not be deceived by the appearance of central Harare into thinking that this is a country now enjoying a problem-free independence. The country has been forged out of one of the most bitter struggles in the post-colonial era. After independence in April 1980, the first decade of Zimbabwe's existence as a free country was marred by a civil war of extreme ferocity that left many thousands of people dead; it was provoked and fuelled in large measure by the destabilisation policy of the South African government at that time. In 1992 famine stalked large sections of the country as rains failed for the fifth successive year.

The Rhodesian colonial system was geared primarily for the benefit of a white minority for whom 'the whole economic system, on the farms as well as in the mines, rested on a cheap and plentiful supply of native labour'. Both the educational system and the health service in Rhodesia were designed for this minority: ten times more money was spent on education for whites than for blacks. In Bulawayo in 1976 there were three general hospitals serving a population of 70,000 whites, while 400,000 blacks had access to one hospital; this was despite the fact that the health profile of blacks was substantially poorer. Missions provided much of the preventive and primary care in rural areas, but more than half of them were closed during the struggle for independence and its ferocious bush war. In disability there was very little provision, and almost none provided by the government for black people.

So with independence there was an explosion of effort in
education and health. The government allocated 22 per cent of its budget to education, which it declared to be the birthright of every Zimbabwean. (This compares with an education budget of around 2 per cent in Britain in the same period.) Within ten years the total school population had jumped from 900,000 in 1979 to three million in 1989. The phenomenal expansion was achieved with the help of an enormous amount of community action, centred on building schools and running informal educational activities such as literacy and night classes for adults. There was a huge desire to get the country going under its new management, and to demonstrate the power of ordinary people to build it.

But the downside of educating so many people so suddenly is that there are very few jobs: to get the humblest position in Harare these days requires five ‘O’ levels. On the streets of Harare itself among the smartly-dressed and quick-stepping office workers are the unemployed and the beggars, many of them women with babies, and many of them disabled. The quiet and spacious suburbs with their swimming pools and magnificent flame trees, once home to white Rhodesians, are now the dwellings of a Zimbabwean upper-middle class who have made it. These are ‘north of the railway line’. ‘South of the railway line’ lie the slums like Mbare and townships like Glenview, and the shanty towns made of packing crates and plastic sheeting that got bulldozed when the Commonwealth heads of state came to town in 1991. Every morning and evening there are long lines of patient people at each bus stop as the city workers wait for two, three, and sometimes more hours for the hopelessly inadequate buses to take them to and from their townships. ‘No foreign exchange, no buses’ is the excuse.

So there are huge problems. The bright promise at Independence of a free, equal, and just society has not been altogether fulfilled. But there can be little doubt that the long and bitter struggle leading up to Zimbabwe's independence has had a very significant impact on the general tone of the country, the aspirations of its people, the energetic communal action, and strong sense of civic consciousness. Against this background, developments in disability work have taken place which reinforce Zimbabwe’s reputation as a country of unusual zest and imagination. Such developments owe much to the sense of struggle that accompanied the emergence from colonial rule, and are deeply affected today by the continuing struggle to build a nation in exceptionally difficult times.
Disability in Zimbabwe

There are three strong threads in the story of disability in Zimbabwe. First, from the 1950s onwards one name stands out as the pioneer and father of work in disability in the country: Jairos Jiri, who, starting from extremely humble origins, during his lifetime set up institutions for disabled people all over the country. Second, Zimbabwe has seen the birth and growth of one of the most vigorous disability movements in Africa, set up largely by people who came through the Jairos Jiri institutions and rebelled against them. Third, soon after Independence the government committed itself to a countrywide CBR policy which has brought rehabilitation to rural areas for the first time. The government is also committed to passing pro-disability legislation.

The Zimbabwe National Disability Survey of 1981, one year after Independence, found a total of 276,300 people with moderate to severe disabilities, out of a population at that time of some eight million — that is, 3.45 per cent were disabled. The survey estimated that one quarter of these, about 60,000, needed rehabilitation intervention. This included people who had been disabled in the

David Zulu, accountant with the National Council of Disabled Persons of Zimbabwe.
violence before Independence, both civilians and ex-combatants. Existing facilities at that time catered for about 9 per cent of the 60,000.

However, this survey was based on some rather questionable assumptions, relying not on house-to-house calls, but on disabled people identifying themselves by turning up at reporting centres; this presupposed that they knew about the survey, could physically reach the centres, and had the full co-operation of their families. (It also implied self-definition of disability, which is probably the most accurate way to measure such statistics.) However, despite such failings it was an expression of the new government’s determination to tackle issues long left untouched and a measure of the energy with which it went about its business. Whatever the actual figure, what was clear from the survey was that existing services were seriously inadequate, especially in the rural areas.

The government’s actions, especially its CBR programme, are clearly and interestingly documented in a recent book by Helen House, Mary McAlister and Cathy Naidoo: *Zimbabwe — Steps Ahead*, to which the reader is warmly referred. This chapter will focus on the formation of the disability movement and its record. For the purposes of our enquiry into social action by disabled people we will briefly consider Jairos Jiri and his work, which set the scene for the emergence of the disability movement, before considering the movement itself.

*The story of Jairos Jiri*

Jairos never went to school. As a teenager from a farm in the Bikita Reserve near Masvingo, he arrived in Bulawayo in the early 1940s looking for work; he had previously tended his family’s goats and worked as a gardener. In Bulawayo he was stunned by the numbers of disabled beggars on the streets: begging horrified and humiliated him. His attitude to disabled people was the same as anyone else’s in the rural areas of the country at that time: disablement came from the displeasure of ancestral spirits, or witchcraft, or, if congenital, was proof of a mother’s infidelity. Disabled people in villages were certainly an embarrassment to their families for these reasons, but in rural areas begging was unknown. Jairos realised that the anonymity of the city and the breakdown of family structures within it made begging not only possible but, in the absence of any services, the only option for most urban disabled people.

He found a job in a bottle store in Bulawayo, but was gripped by the necessity of doing something about the disabled beggars. So he
began. His job at the bottle store involved delivering orders on a bicycle; when disabled beggars came to the shop, he used the bicycle with its large carrier to take them to hospital for corrective surgery. The first person he picked up, a boy crawling along the pavement in rags, was eventually able to walk unaided after extensive treatment. Those whom the hospital could not treat, particularly blind people, he took home to his two-room house in a township. He had no finances other than his wages, but built a shack behind his house, where he got a friend to teach blind people to make baskets. He earned extra income for these activities by selling sweets on street corners, and opened a vegetable stall by his house. He then persuaded a shoe-maker to give instruction in shoe repairs to the growing crowd of disabled people who came daily to the packing-case workshop behind his little house.

People thought he was mad. The Municipal Authorities demanded that if he was going to do charity work, he should register as a proper organisation. When he tried to do just that, the Native Commissioner told him the idea was utter nonsense and he was not prepared to consider it; Jairos should not waste his time. It was not until a different Native Commissioner was appointed with more liberal ideas that Jairos finally managed to register the 'Bulawayo and Bikita Physically Defective Society' in 1950.

That was the start: one should not underestimate the measure of his commitment in what now seem like the dark ages. By the time he died in 1982, Jairos Jiri had spent 35 years, the whole of his working life, setting up centres for disabled people all over the country under the name of the Jairos Jiri Association. He had established seven children's centres, three training centres, three farms, six sheltered employment workshops, and one old people's home, plus commercial funding for craft shops. It was an extraordinary achievement by any standards, in a country where disability was almost totally neglected before he came along. It was the more remarkable given his background, complete lack of education, and the attitudes of the day. The work he set up continues.

Lessons from the Jairos Jiri experience
As a case study, the work of Jairos Jiri sheds light on the historical process behind work in disability that is common in many parts of the world: the transition from no services at all, to charitable institutions, to a growing political consciousness among disabled people (as we will see below) and the formation of a movement. It
also reveals the powerful tensions that exist between the 'charity industry', with its focus on individual need, and the movement of disabled people campaigning for universal rights.

With the awareness that we have now, focused on empowerment and equality, it is easy to be dismissive of past efforts that seem to stem from outdated notions of charity and paternalism. But we need to keep the historical perspective in mind. In Britain, Victorian philanthropy, with its gloomy, monolithic institutions and armies of determined do-gooders ladling out soup to the poor, laid the basis for present-day voluntary action, not to mention the establishment of the Welfare State. To criticise the Victorians now with our present attitudes is like saying that the USA should have put men on the moon in the 1920s: the time was not right.7

Similarly Jairos Jiri, with all his paternalism, played a vital role in preparing the ground for the response to disability that has developed in Zimbabwe over the last 15 years. To dismiss him as a misguided paternalist is to be unaware of the historical moment.

Forming a disability movement

The disability movement in Zimbabwe grew out of the institutions that Jairos Jiri created; the leaders of the movement themselves are nearly all graduates of them. Without Jairos Jiri it is very difficult to see how the movement could have started and developed as it did: he provided not only an education and training for hundreds of disabled people who would not otherwise have had one, but also the greenhouse in which the movement could take root and begin to grow, before transplanting itself into the world outside. Criticism of the institutions may well be fair, with the knowledge and awareness that now exists, but they were the test bed and the launch pad for what came next.

Alex Phiri, already quoted in Chapter 3, was abandoned by his parents when he lost both legs in a road accident at the age of eight. He was one of a group of people who became disillusioned with life in a Jairos Jiri institution in the early 1970s. He showed outstanding talent as a painter and was seen as a valuable asset by the institution where he lived: his paintings were prominently displayed, and added considerably to the impression made on visitors. They were also sold in the craft shops and brought in income for the Jairos Jiri Association. The Association therefore wished him to work for them permanently as an artist, but Alex had other ideas: he wanted to continue his studies, as far as university if possible. The institution
refused his request to go to a school where he could work for his ‘A’ levels, so he went by stealth and by force of personality: he hid in the back of a truck that was going to the school, and demanded to be accepted.

During his time at a Jairos Jiri institution, Alex and others formed what they called the Kubatsirana Club (from a Shona word meaning ‘to help each other’). This club organised excursions into the surrounding countryside for picnics, an activity supported and encouraged by the institution, which provided transport. But Alex and his friends used the outings as opportunities to discuss their problems as disabled people living in an institution. They then formed what they called the ‘Inmates’ Representative Council’, an indication of how they perceived themselves at that time. Alex picks up the story:

_We decided to transform our club into a registered organisation, ‘The Council for the Welfare of the Disabled’. The name confused Jairos Jiri because it sounded like a service organisation, but what we had in mind had nothing to do with service; it was an advocacy or pressure group. When Mr Jiri realised we were advocating power for disabled people, he suddenly felt threatened. 1974 was marked by a battle to get the organisation registered. We eventually got it registered in 1975._

The response from Jairos Jiri was, perhaps, understandable but disappointing. His commitment to what he was doing was never in question. What had been achieved since the first rag-clad beggar had been scooped off the pavement into his bicycle carrier was indeed amazing, but his vision of the capabilities of disabled people was, for the new generation, much too limited. Joshua Malinga, now Secretary General of SAFOD (Southern Africa Federation of the Disabled), was another of the early members of ‘The Council for the Welfare of the Disabled’. He himself had indeed been rescued from oblivion by Jairos Jiri as a non-walking village child with polio, but he describes with some despair how he was told by Jairos to learn shoe-repairing as his trade. Like Alex he wanted a proper education, and after a great deal of pushing he finally persuaded the institution to hire a teacher who would teach them ‘with books’.

Joshua, Alex, and their friends felt that times had changed greatly since Jairos first started his work, but the Jairos Jiri Association had not changed with them. The struggle for national independence in which the whole country was engaged had its effect on their consciousness as disabled people, but the Association was not
committed to and did not understand integration; rather its institutions tended to be terminal abodes for those who entered them, and they were touching only a minute proportion of the disabled people in the country: they held altogether about 1,000 people at any one time. Joshua and the others saw that such institutions would never be able to integrate those they did help, or reach the majority beyond the institutions, who were still untouched.

So they set off with their own organisation, without knowing where they were going, but with the conviction that certain principles were inviolable. The most important of these were that disabled people should be intimately involved in the planning of the services that affected them and that they had the same rights as any other citizen. Alex again:

_We didn’t have a clear plan of action. We operated on the enthusiasm of success rather than real structure. The constitution itself was very simple. It emphasised self-help for disabled people, but gave no guidelines as to how this should take place. Basically the organisation provided a monthly forum for disabled people in Bulawayo to protest against the shortcomings of the institutions and to share their personal problems._

**The National Council of Disabled People of Zimbabwe (NCDPZ)**

By the end of the 1970s, with Independence in the offing, Jairos Jiri had become a highly revered figure; his name was a household word equated with work in disability. But Joshua Malinga and his friends were deeply concerned that this institutional approach, which depended on private charity, which was not committed to integration, which had a limited idea of what disabled people were capable of, which felt threatened by the idea of disabled people having a voice, and above all which made no demands on the government, would be adopted by the new government for lack of any better vision. Such an approach conveniently let the government off the hook altogether.

It was this fear in particular that spurred them to press on with forming their own organisation which would demonstrate an alternative: in September 1979, six months before Independence, they produced a paper outlining a policy on rehabilitation, containing 25 detailed points. The paper proposed the formation of a National Council for Welfare and Rehabilitation composed of
government departments, voluntary agencies, organisations of disabled people, trade unions, and rehabilitation specialists. The council would take charge of all matters relating to disability in the country. In particular the paper strongly recommended pro-disability legislation, and community-based rather than institution-based rehabilitation. Such a council was never formed, but the proposals had an impact on government thinking and certainly contributed to creating the positive approach to disability that was demonstrated by the National Survey and the adoption of a country-wide CBR policy.

The next landmark in the development of the movement was when Joshua Malinga attended the Rehabilitation International Congress in Winnipeg in 1981, the watershed in the history of disability where Disabled People's International was born (already referred to elsewhere in this book). Before going, he had no idea what awaited him, but, like Mike du Toit from South Africa, he was fired in Winnipeg by the power of disabled people speaking out for their own rights against the weight of the medical rehabilitation model espoused by the professionals. Alex continues:

Before Joshua's trip to Canada we were simply a support group for one another; we had no political analysis. It was only after his discussions with the equally frustrated disabled people from around the world that we began linking our problems in Zimbabwe to social, economic, and political issues.

The first thing they did was change their language. They dropped the word 'welfare' and called their organisation the 'National Council of Disabled People of Zimbabwe' (NCDPZ). From the start they saw its purpose to be primarily a pressure group to create new thinking about disability in the government, among professionals, in institutions, in the general population, and among disabled people themselves. The new thinking meant that disabled people should be able to contribute and be fully integrated into all aspects of life, share in the planning of rehabilitation services, and, crucially, have their rights recognised by pro-disability legislation on the statute book.

In order to function effectively as a pressure group, it needed to be a movement, which meant building a membership. Building a membership meant more than just talk: it meant practical projects. They began a small knitting and dress-making workshop, Afro-Knit, employing six disabled women in Bulawayo. But urban disabled
people were better served by existing services than those in rural areas, for whom there was virtually nothing. Over 70 per cent of the country’s population lives in the rural areas and, if NCDPZ were to make any impression there, they needed an office, full-time staff, and a vehicle. In 1982 NCDPZ started an outreach programme, the Rural Membership Development Programme, with support from Horticultural Therapy and funding from Oxfam (UK and Ireland).

The aim of this programme was to identify disabled people and their needs in the rural areas, conscientise them, help them to acquire medical and rehabilitation services, and enhance the general educational levels of disabled people through help with school expenses. They aimed to set up practical projects which would make disabled people more self-reliant, and also encourage integration through working jointly with able-bodied people. Such projects would give disabled people self-confidence and a moral boost. At the same time they would reveal to able-bodied people the potential rather than the limitations of disabled people.\(^{10}\)

The Rural Membership Development Programme (RMDP) was started with a network of contact people in rural areas whose function was, and is, to assist in the implementation of the programme. They include disabled people, church workers, district councillors, chiefs, headmen, school teachers, hospital staff, and members of the Organisation of Rural Associations for Progress (ORAP). ORAP has been an important influence on the thinking behind the programme. After Independence many foreign development agencies established themselves in Zimbabwe, and funds flowed in, all aimed at 'projects'. ORAP is critical of this approach: it feels that a purely project-focused development strategy is artificial and neither recognises nor encourages the natural processes that are part of people's lives. ORAP does not see development in terms of buildings rising from the bush, or the number of wells dug, but in the gradual change in people's consciousness and ability to manage themselves and their environment successfully. 'Projects' should simply be a means to this end, not an end in themselves. This matched exactly the approach of NCDPZ when the rural membership programme started, which was to get away from concrete institutions and expensive infrastructures, and use existing structures to work with people in their own contexts.

Once disabled people in a particular area have been identified by the contact people, they form themselves into a branch of NCDPZ,
supported by a development officer from the office in Bulawayo. Each local branch is responsible for identifying other disabled people, encouraging solidarity between them, facilitating their educational and rehabilitation needs, and setting up practical projects. A branch consists of an elected executive committee of disabled people which may co-opt others, including able-bodied people, as necessary. They may use a school, church building, council offices, local clinic, or the open air for their functions.

Ephraim Mafura is the chairperson of the Chirumanzu branch of NCDPZ. Chirumanzu lies about 250 miles south of Harare, and a little to the north of Masvingo and the impressive ruins of Great Zimbabwe. The area is scrub and bush, punctuated by widely scattered villages up to ten miles apart. In the centre of it there is a mission which runs a small hospital. Like many other parts of Zimbabwe it has been affected by drought, and at the time of my visit there to gather material for this book, the government was distributing food. Significantly, the disabled people I interviewed had not received anything.

Ephraim walks with a crutch as the result of polio, and spent his childhood in a Jairos Jiri institution.

I left the institution eventually and was employed by my brother, who had a grinding mill at home. I worked for almost ten years for my brother operating the grinding mill. But after ten years there were some problems between me and my brother: he was not paying me a proper wage. He said, ‘I cannot pay you a proper wage, because I am looking after you.’ But I said, ‘How can you say you are looking after me when I am doing the work of any normal person?’ You see, the attitude towards disabled people is like that.

So Ephraim left his brother’s grinding mill and decided to start, with others, a branch of NCDPZ. It now has more than 100 members, scattered over an area about 50 square miles. With such a widely scattered population, the logistical problems of facilitating a group of disabled people are staggering. How do people move around, especially if they have mobility impairments? Ephraim explains:

We have a big problem getting people together. If you want to catch a bus, you have to walk at least ten or fifteen kilometres. If you can’t walk, well, there are very few private vehicles, so it is extremely difficult to get lifts. It’s a huge problem. We meet at the mission. They give us accommodation for the night. We pass word through schools
and the Post Office agent. This works; we are able to meet, if people have enough warning.

What are the issues that face people in an area like Chirumanzu? In a rural area where people are not even able to grow enough food because of drought, the options seem limited: survival is what is at stake. Simon Tevera is 50, lost an arm in the war, and is a member of the Chirumanzu branch:

I have two cattle left now. I had eight before the drought. If these die, I don’t know what I shall do. There is a government hand-out of maize every six months, but it is given to those who have participated in a food-for-work project, which usually means road building and maintenance. Disabled people cannot normally join in such schemes, so they get missed out at the food distribution.

So what is the meaning of ‘disability politics’ for Simon? What does being a member of NCDPZ mean? Simon is very forthright:

We do not speak about politics; we speak about survival.

But Ephraim explains that there is something that can be done ‘politically’ for people like Simon. He is pressing the NCDPZ office in

Simon Tavera, Chirumanzu District, disabled in the war before Independence:
Bulawayo to take up the case of food distribution at government level, and to ensure that disabled people are not missed out. He believes that this is exactly the kind of action the office should be taking.

There were some surprises in these interviews in Chirumanzu. Many of those interviewed were aged over 50 and had grown-up children. But none of them said that their children were helping them in their old age. Michael Mhene, for example, was forthright about large families:

_Let me tell you: it does not work, this idea of children looking after their parents. I have five sons and they do not even visit me, let alone look after me. I hope they do not make the mistake of having many children. Many children increase poverty._

Life in the rural areas of Zimbabwe is very grim indeed, especially when it does not rain for five years, especially when you get old, and especially when your children do not look after you.

**The mechanics of social action for social change**

An organisation like NCDPZ has an extremely difficult role. It was evident in these interviews that in such desperate circumstances the rural members of NCDPZ were looking to it for their survival. But the leadership of NCDPZ sees the organisation primarily as a pressure group, not as a service provider. This has led to much misunderstanding and not a little hostility on the part of disabled people, who say: 'We can't eat politics'. 'Politics' tends to be equated in rural areas with tribal rivalries and corrupt officials; the idea of a pressure group is not easy to understand for people who are not exposed in their normal lives to the mechanisms of power or the process of raising issues as matters of principle. They see NCDPZ receiving foreign funds, and wonder why these are not translated into practical help in the form of services.

What can NCDPZ offer to people like Simon Tevera by being a membership organisation? There is an obvious danger that the well-educated leaders of the organisation in Bulawayo develop a very different agenda from the rural members whom they claim to represent. But is that really the problem? An evaluation of the RMDP in 1988 pointed out that many rural members had, unsurprisingly, absolutely no experience of decision-making of any kind, and turned up at branch meetings in the hope that NCDPZ would be able to solve their problems. In other words, they did not have an agenda of their own, and were expecting the head office to provide one.
So we are into the classic vicious circle of development: 'The active nature of under-development and poverty determines people's understanding of development, which in turn affects the kind of development work that can be done.' In other words, to begin to break out of poverty and under-development requires awareness and understanding among those who are poor and under-developed, but it is precisely their poverty which prevents them from gaining awareness and understanding.

NCDPZ is faced with two very important issues here: the first is whether it can become engaged in real development work that will benefit people like Simon Tevera and Michael Mhene. The second is how to bridge the gap in awareness and understanding between the urban leadership and the rural membership. Jabulani Ncube was the director of NCDPZ for several years during the 1980s. He now works as a consultant for ADD (Action on Disability and Development). On the question of leadership he says:

There cannot be an NCDPZ without the existence of a coherent membership. If we are going to be talking about movements of disabled people, then we ought to define very clearly in our minds what it constitutes. A movement is not simply a few individuals at the top of an organisation conveniently calling themselves the leadership of a movement. I am not saying that that is precisely the situation, but this is a challenge for a number of organisations of disabled people that I know, not only in Southern Africa, but also in other countries where the creation of a true movement is threatened by such a situation.

So the creation of a viable movement means a great deal of work with people in both the rural and urban membership programmes. It is not enough to tell people about their rights and expect them to be capable of securing them at once. If people are to become more independent and capable of fighting their own battles, time must be invested in training, orienting, and conscientising them about the issues and how to deal with them. This requires considerable skill, patience, and tact in the development officers, who may often be tempted to deal with particular cases and individual matters themselves, rather than get the individual or local group to act. But every time the development worker does that, the person who should be learning is deprived of an opportunity to do so.

Then there is the question of 'projects'. It is significant that after eight years of experience in the RMDP with small-scale gardening, poultry, bakery, and sewing projects, disillusionment has set in. The
number of people engaged in such projects has been small. Some of the projects have been over-ambitious, relying on outside inputs and advice. At the same time there is a clear recognition by the leaders of NCDPZ that without some material benefits, there will be no rural membership: indeed, people cannot eat politics. Sometimes the projects have failed because people do not have the mobility appliances to be able to function in them; the supply of essential appliances is a vital service at the base of any disability programme.

In urban areas the problems are different and on the whole have easier solutions. On the negative side it costs money to live in a town — to eat, to rent a house, and to move around. On the positive side the opportunities for income-generating activities are much greater. In 1991 NCDPZ opened a supermarket in Bulawayo which employs a dozen disabled people, and has a turnover of several thousand Zimbabwean dollars a month. It is a bold and ambitious project that has paid off and is a positive step towards making NCDPZ less dependent on foreign funding.

And what about relations with other players on the disability scene, like Jairos Jiri and the government rehabilitation programme? The abrasive militancy of the founders of NCDPZ, which certainly
Zimbabwe did not win friends among many professionals, for example, has been replaced by a more constructive approach which sees the importance of close co-operation in order to build a unified service system in which disabled people have an important voice. For example, NCDPZ workers are involved in the training of government rehabilitation assistants (the equivalent of rural health workers). NCDPZ works closely with the government rehabilitation service for referrals and supply of appliances. With Jairos Jiri there is some co-operation: that Association has changed too, and is now more aware of the need to prepare people for life, rather than give them a permanent home; it has put itself on the line on several occasions to make this point, which has created painful confrontations with ‘inmates’.

The problems faced by NCDPZ in the rural areas, the difficulties of building a cohesive movement, and the stresses and strains of trying to build an organisation not dependent on foreign funding are common to most (if not all) grassroots development groups struggling for social change in developing countries. These difficulties do not in any way obscure the successes of NCDPZ, which are considerable. At a general level it has succeeded in creating a new consciousness of disability issues in Zimbabwe. Access to buildings is far better now than ten years ago. Public transport makes some provision for disabled people. Integration in schools is a reality for many children. Pro-disability legislation is about to be passed. These are no mean achievements.

Let the last word here go to Jabulani Ncube:

_The entire system of the world today needs to be questioned continuously, and possibilities for alternative strategies must be constantly explored. There are no easy answers; development has no recipe. What we require is commitment to action by people in the different nations and societies to develop themselves._14
India: social action in a highly complex society

‘One who always sees all living entities as spiritual sparks becomes a true knower of things.’ (Sri Isopanisad)

Fact file

Population: About 850 million in 1991, increasing by 17 million (the number of people who live in Uganda) every year. The biggest state, Uttar Pradesh, has the same population as Egypt, Sudan, Ethiopia, and Somalia combined (134 million).

Languages: 15 official languages and more than a thousand other languages. The census of 1971 listed 1,652 languages spoken as mother tongues.

Religions: Hindu (82.64%), Muslim (11.35%), Christian (2.43%), Sikh (1.96%), Buddhist (0.71%), Jain (0.48%), others (0.42%)

Infant mortality rate: 97 per 1,000 live births (1988)

Life expectancy at birth: 58 years

Literacy: Men 64%, women 39% (1991)

Government: India is the largest democracy in the world, with a multi-party system and both federal and state legislative assemblies.

Background

Anyone approaching India from, say, Africa or the Middle East is in for a shock. Nothing compares with India, and nothing can prepare you for it: it is a universe of its own, with staggering numbers, distances, and diversity. The newspapers are littered daily with
horrors never reported in the West. Even to attempt to write about India with any degree of clarity and cogency seems a hopeless task, especially for an outsider.

The difficulty in a book like this, which is trying to chart constructive pathways through the maze of social attitudes about disability, lies in identifying the agents of change in a highly charged, rigidly stratified, and extremely complex culture with many fault lines and zones of confrontation. India presents an immensely difficult problem in any discussion about development because, in approaching the subject of changing attitudes, it is impossible to disentangle culture from religion and politics. What constitutes 'local culture', and what is its part in creating change? To what extent is culture sacrosanct, especially when it is enshrined in religious dogma, and especially when that dogma seems to be the product of power games and domination by one section of society going back thousands of years? Aid agencies and development workers are often criticised for ignoring or undermining local culture in their desire to effect change; since these workers tend to be educated on Western models and their funders are usually from the West, this leads to the charge of cultural imperialism.¹ We have to confront the question of whether social action, including working for change in attitudes to disability, is just another form of cultural imperialism.

Gods, Gandhis, and film stars: the pantheon of modern India.
Culture, however defined, is not a static state, but the dynamic interaction of many forces, including interaction with other cultures. Western culture itself is undergoing constant change, in which the influence of Eastern philosophies cannot be ignored; it seems somewhat patronising to suggest that other cultures are immutable and should be preserved in some kind of time capsule. But in any case it is not as though social action is foreign to India: it was India that, under such moral giants as Gandhi, pioneered it as a strategy for change on a national level. India has set an example for social action on the grand scale which has remained an inspiration to millions throughout the world.

Not only is modern India the largest democracy in the world in terms of an elected government. Throughout the country there is also a vigorous culture of social action over a range of issues, from deforestation to bonded labour to atrocities by landlords. ‘Social action centres round mobilisation of oppressed people through a sense of moral outrage against injustice and inequality, for survival and identity.’

One of the main arguments of this book is that a change in attitudes to disability is not just for the benefit of disabled people themselves, but is an important indicator of a wider, deeper growth in consciousness among human beings which is part of valuing the planet and those who live on it. Injustice is not confined to any one culture, and nor is the moral outrage that tries to counter it: both occur everywhere. Although social action on disability is comparatively new in India, it follows logically in the pattern for action already established in other areas of the struggle for social justice in the country.

Despite the bewildering complexities of India and the huge risks inherent in any simplified analysis, some attempt must be made to set the context for the very important experiments in social action on disability that are taking place in the country.

**Rich and poor**

After Independence in 1947 the Indian government embarked on a series of five-year plans which were aimed primarily at tackling poverty. The country has made rapid strides in industrialisation: there is hardly a car on the roads which has not been assembled within the country. India has its own nuclear and space programmes. The Indian film industry is the largest in the world, in which moguls amass colossal fortunes, while rags to riches for stars
and starlets is a proven possibility. In agriculture the green revolution of the 1960s and 1970s has made India more than self-sufficient in food: overall surpluses are available not only for its own regional shortages, but also for occasional relief to other countries.

These successes have not, however, made a significant impact on the problem of poverty: out of the total population, half (that is at least 400 million, which is about a twelfth of the world’s population) are living below the poverty line. Eighty per cent of the population lives in villages, where the poverty is most apparent. The technological successes in agriculture have simply widened the gap between rural rich and poor, since improved agricultural techniques frequently mean more mechanisation and less human labour. Those who have fertile or irrigated land have done well; the landless and those on marginal or dry land have been left behind. It is the yawning divide between rich and poor in the rural areas, or rather those who have land and power and those who do not, that has created the need and the context for social action in much of India.

**Caste**

Caste is essentially a Hindu characteristic; the whole Hindu worldview is based on circumstances of birth, not on belief as understood in the West. Hinduism is inseparable from community and family. There is no one set of scriptures revealed at a particular moment in history, but a whole shared experience going back thousands of years which is still evolving; it is a shared culture rather than a religion, with the family and social relationships at its heart.3

For traditional Hindus, caste is an integral part of their entire worldview: status is acquired by birth, not achieved by effort, and cannot be changed, not even through education and taking on sophisticated jobs. The only real option to escape from this structure is to renounce Hinduism in favour of another belief system, as was done by a famous harijan (‘untouchable’) leader, Dr Ambedkar, who became a Buddhist in the 1920s, taking about three million other harijans with him. But even among non-Hindus in India the influence of caste can still be felt.

There are four main caste groups and many sub-groups. These derive originally from the broad separation of the populace, dating back four thousand years, into occupational roles: priests (Brahmins), warriors (Shatrias), merchants (Vysias), and servants (Sudras). Others, notably the tribals and people referred to historically as ‘untouchables’, are considered outside and beneath the caste system.
Gandhi insisted that the ‘untouchables’ should be referred to as *harijans*, or ‘children of God’, and the term ‘untouchable’ is no longer used. The term *harijan* itself has now been officially discarded in favour of ‘Scheduled Castes’. This term derives from a government policy of positive discrimination in favour of these people in the job market, where they are allocated (or ‘scheduled’) a certain percentage of jobs in the government sector. (Confusingly the term ‘Backward Classes’ is the official designation of the lower castes, the *Sudras*.) But such positive discrimination has, many Indians would contend, served only to perpetuate and indeed solidify the caste system, because it means that people get jobs on the basis of caste rather than merit. It is seen as a sop to keep the masses from grumbling too much.

The term *dalit* is used to include all oppressed people: the scheduled castes, landless labourers, bonded labourers, and tribals. It is not therefore congruent with *harijan*, although *harijans* are *dalits*. Since most *dalits* live in villages, it is a term most often heard in reference to issues in rural areas. But we are not speaking of a minority: over 50 per cent of the population of India is composed of *dalits*—*harijans* and tribals, people who are technically ‘beneath’ all the other castes. There are thus more people outside the caste system than within it.

Whereas cities provide some general anonymity and therefore a potential weakening of the caste system, village life is still dominated by it. ‘Scheduled castes’ live in clearly defined areas of the village, and most land is in the hands of higher-caste people. In extreme forms of the system, a high-caste Brahmin will not only avoid associating with the scheduled castes, but will regard everything they touch as unclean. Violence between castes in rural areas is commonplace, mainly atrocities by landowners against *dalits*.

Caste encapsulates politics, religion, and culture in one overarching structure that poses a formidable obstacle to constructive change. As a *harijan* leader in Tamil Nadu put it, ‘All men are born unequal, and women hardly count.’ The greatest difficulty of all is that caste is more or less universally ingrained in the entire social and cultural fabric, including that of its victims. This has a devastating effect on the self-image of those at the bottom of the ladder. The perception of themselves as inferior beings is very common among *dalits*:
Ironically the victims have internalised the values about their status as born unequal. They have legitimised the mythical destiny imposed by their *karma* to live out the punishment for the guilt accumulated in their past lives. The resulting damage is so deadly to the whole of their personality that a profoundly wounded psyche is the prime characteristic of the *dalits*, whether they are highly educated or totally illiterate.\(^6\)

A profoundly wounded psyche is not a characteristic only of *dalits*. A social and religious belief system which ranks human beings from 'pure' to 'impure' would appear to carry a built-in prejudice against disabled people, who are not perceived as 'whole'. In traditional Hindu belief, disability is a punishment for misdeeds in a former life. If a change in attitude and consciousness on disability has to start with self-esteem and a positive self-image on the part of the disabled person, the belief in *karma*, or destiny, that inflicts disability as an inevitable and deserved punishment for failures in past lives, is not a very encouraging starting point.

The wounded psyche is the result of centuries-old traditions, beliefs, sanctions and customs. The disabled person herself has to change; she has to claim within her family and environment the space for this change. These processes involve a Herculean task. True integration requires much energy and time.\(^7\)

**Father Cutinha**, Director of the Divine Light Trust for the Blind at Whitefield, Bangalore, describes the situation of caste as it relates to disabled people in this way:

> Disabled people form a sort of fifth caste, below the other four. But among disabled people themselves, disability does to some extent cut across caste boundaries, so that high-caste and low-caste disabled people may be happy to be in the same group. But where the economic cake is small, there it acts. For example in the rural areas it operates. And among higher castes, although they do not say this, their behaviour indicates that it does operate over marriage. A disabled woman, for example, stands very little chance of getting married in the higher castes. I have spoken to Brahmins, blind, who have been through this school, and I have said to them, 'I have a feeling that your parents did not accept you.' And they have broken down and said, 'Yes, that is so.' I am inclined to think caste does operate strongly with disability, especially among the higher castes.
Women
The position of women in India places them among the most oppressed in the world. This oppression begins with the Hindu texts, which contain numerous categorical statements emphasising women's inferior status. Thus Manu, a famous law-giver of c. 200 BC: 'In childhood a woman must be subject to her father, in youth to her husband, and, when her lord is dead, to her sons. A woman must never be independent.'

Most women in India, especially in the rural areas, lead an existence of extreme subservience, with very little control over their own lives. The few (mainly urban) women who have succeeded and risen to prominence in a completely male-dominated society do not indicate a general improvement, at least not in the rural areas.

A disabled woman therefore suffers a multiple handicap. Her chances of marriage are very slight, and she is most likely to be condemned to a twilight existence as a non-productive adjunct to the household of her birth. At best she may be the object of misplaced sympathy which regards her as helpless and unable to do anything for herself or for the family; or she may well be kept hidden in order not to damage the marriage prospects of siblings; alternatively she may be turned out to beg. It is small wonder that many disabled female babies do not survive.

The Association of the Physically Handicapped in Bangalore runs a training programme in its main centre for both disabled men and women. The problem of what happens to young disabled women when they leave is acute; usually they return to what amounts to the prison of their own families, with no prospect of marriage. That is why Hema, a founding member of the Association, has recently started encouraging women leavers to form their own separate independent living groups away from their families.

Parvathi, Vasanthi, and Hamsaveni are one such group, who live together in a house on the outskirts of Bangalore, earning their living through tailoring. Hamsaveni, aged 20, explains her motivation for taking this option:

*If I was at home, my parents would be very protective and not give me any freedom. Being at home is a trap. In this group I can come and go as I like. We feel free in this group and we also feel secure. We earn our living by making school uniforms and making clothes to order. We have good relations with our neighbours; we do all our own shopping. We feel good about ourselves and our neighbours respect us.*
Women waiting for the start of a disability sangham meeting, near Bathallapalli, Andhra Pradesh.

This is a triumphant story. Centres for Independent Living (CILs), which have become an important feature of the disability movement in the West, starting in California in the 1960s, are certainly an option for disabled people all over the world, especially in urban settings, and especially for women with little chance of marriage.

Women also act as carers for disabled children. As we will see in the case study of Jordan and the Occupied Territories, neglect of disabled children by their mothers is not usually a deliberate choice, but one forced on them by lack of services; as soon as services are available, they are seized upon. In India such services as exist are generally available only in the towns. Most women in rural areas have no access to services for their children; in the last part of this chapter we will see examples of where social action groups are trying to address this problem.

Social action on disability: the background

On the basis that 3 per cent of any population is disabled to a degree which needs specialised services, there are, at the very least, well over 25 million disabled people in India. It would be quite impossible here to survey the whole scene, and in any case comprehensive statistics do not exist: even the number of institutions is not known accurately.
The Indian government divides disabled people into four categories: blind, deaf, orthopaedically disabled, and mentally retarded. Both government and private institutions for all these categories exist in cities, but cater for a tiny fraction of the number who need services. The rural areas have very little provision for disabled people.

There is no single cross-disability movement in India which unites all disabled people. Blind people, deaf people, and those with orthopaedic impairments have their own single-disability national federations, but there is very little linkage between them. The logistical problems of organising a single cross-disability movement, with so many languages, such vast numbers, and distances so great, are formidable. With over 14,000 indigenous rural development NGOs working in India, the task of coordination and information-sharing about any aspect of development becomes daunting.

As it has done for the Scheduled Castes, the government has allocated a percentage of jobs within the government sector to disabled people: blind people, deaf people, and those with mobility impairments get one per cent each. But apart from the fact that these percentages are not properly applied or monitored, the same problem occurs as with the other job allocations: these measures are regarded as a sop by the higher castes to stop the moaning lower down the ladder; rather than abolish the hierarchy, such measures reinforce it. Father Cutinha again:

*Take job reservations for disabled people. The higher castes say, ‘Yes, give them these things, no problem, but so far and no further’, just as they do with the reservations for the lower castes. So there is a lack of seriousness in understanding the problems of disabled people, just as there is a lack of seriousness in understanding the problems of the dalits. It’s the same thing.*

These allocations are not enshrined in law, but have the status of general agreement. They do not constitute an inalienable right.

However, weighed against all the negative factors of caste, violence, and the oppression of women are the counterbalancing factors of a society which has a culture of democracy that would be the envy of most other developing countries. Government structures reach into the remotest villages, and many of the thousands of indigenous voluntary agencies working in rural development receive government funding. In the state of Tamil Nadu alone, there are over 1,500! There is an enormous interest in and prodigious
work on social change in rural areas, based on a wide range of philosophies. We will see three contrasting examples in detail below.

**Breaking the mould of charity**

Although there is a vigorous and impressive debate and committed action on development issues in general in India, disability is still dominated by the charitable approach based on large, often privately funded, institutions for a limited number of people. The task of breaking this mould and treating disability as a social and political issue seems formidable. Father Cutinha has been Director of the Divine Light Trust for the Blind in Whitefield, Bangalore for over forty years. Able-bodied himself, with a keen perception of the structural causes of disability, he charts with great clarity how his own consciousness has evolved over the years from charity to the social model:

> At the beginning my only motivation was to help out. We opened as a school. I taught different things. I had no concept of development at that stage. The social-work concept at that time, which I was schooled in, was to play a key role in helping others, but the potential of these others was not fully recognised. Helping a person was the philosophy: taking them off the streets, providing food and clothing, giving them education, that kind of thing. I do not now deny that the help is required, but it is not the engine of development itself. This attitude did not begin to change until the early 1970s. So when I started, I was part of that social-work culture. But later on the socio-political analysis came through to me, not in relation to disability per se, but in relation to poverty generally.

The 1960s and 1970s saw the development of a strong Marxist trend among some development workers in the analysis of poverty in India. Father Cutinha was influenced by it, but had reservations:

> Although I agreed to a large extent with the kind of Marxist analysis of poverty, there was one major thing missing from it, and that was the cultural context. It is not just a question of rich or poor here: there are cultural and religious determinants such as caste. And apart from caste there are cultural patterns like early marriage, which causes disability because women are often not mature enough physically to give birth safely, a situation worsened of course by the absence of ante-natal and post-natal care.
But another problem of the Marxist analysis was that it simply stopped at 'the deprived'. It did not consider the particular situation of disabled people, who actually form a kind of fifth caste. So I said to the Marxists, 'You are ignoring a tenth of India's population.' They replied that they are simply part of 'the deprived'. But I said, 'No, they have special needs, they are in a group by themselves. They are marginalised among the marginalised.'

So the thought was: why not build up a movement who would claim their rights as disabled people? We thought: 'Nobody's going to help, so we should stand up and fight ourselves.'

In the decision to work for the establishment of a disability movement, Father Cutinha and his group were heavily influenced by one major factor: the question of grant in aid for institutions. By the end of the 1970s a number of institutions and schools for disabled children had been founded. They decided to request the same facilities and funding as those working with normal children. It meant adding just one sentence to the legislation. But despite intensive lobbying with legislators, they met with indifference:

We went to every leader of every party and explained to them the position. We said, 'This is a common factor; disability has no party.' We worked for six months like this. We must have approached nearly 200 politicians of different parties. It was just a matter of adding one sentence to the code. We waited with great apprehension for the crowning of our work. But when it came to the crucial moment, not a single person in the legislative assembly raised the matter. It just was not mentioned. No one, just no one mentioned it.

I had a good friend among the Communist Party members, a very progressive man. He called me and asked, 'You are disappointed?' I said, 'Of course, bitterly disappointed.' He said, 'Tell me: how many votes can you give me?' I replied, 'Well, four or five perhaps.' He said, 'You must learn this lesson: unless disability becomes a movement on its own, it will not survive as an issue. It must become part of the civil rights movement.'

This was a turning point in Father Cutinha's own understanding of political processes. In his opinion it is impossible even today to talk in terms of political action by disabled people in the way that this Communist friend meant it. There are a few exceptions, like the National Federation of the Blind in Delhi, which takes political
action at the national level on behalf of blind people; but nobody else, says Father Cutinha, among Indian disabled people is prepared for political action. There are, according to him, two reasons: first, disabled people themselves are not yet ready for it. Second, institutions are still the dominant gathering point for disabled people, but those in these institutions, lulled by inertia, do not even question the assumptions of their own boards. The boards consist mainly of people, both able-bodied and disabled, who have made an emotional and charitable response to disability. A familiar response from the boards of institutions is: 'We are doing something. Need we do more? We don't want to rock the boat'. Father Cutinha comments:

> By and large the boards that manage the services are no different from what they have always been. Nothing will change until aware disabled persons themselves come up and run their programmes. But this will take a long time, because when disabled people try to take over the services, the boards react by saying they are ungrateful. Even when disabled people get on to one of these boards, they tend to be those who are not yet sensitised or aware politically.

> When I approached one of our board members here to take direct political action, he demurred. He said he didn't want to upset government officials, and said he would approach 'his contact' in the relevant department. It is always like that. You work with 'your contact in the department'. So we don't think in terms of demanding it as our right, but in terms of getting it because 'our boy' is in the department. And if you don't have a boy in the department, you don't get it. Generally this is how things work, and most boards function on that basis. They don't see the need for more principled work. A serious intellectual commitment is not there, either among disabled people or among able-bodied people.

From institution to response centre

Father Cutinha then quotes the first draft of the national policy on education published by Rajiv Gandhi in 1985, in which there was no mention of disability at all. But to his amazement, people working in disability were not only not aware of this, but they did not even know that a new national education policy had been published. They were not alert to the strategic importance of keeping an eye on such things. So he and his group sent telegrams asking why it had
been left out; the result was that in the final draft in 1986 there was a mention of ‘the handicapped’. Unless there is an awareness of the mainstream political issues as they affect disabled people, no meaningful change is likely.

There was a moment of truth for Father Cutinha himself when it dawned on him, 35 years after starting his school for blind children, that only about 5 per cent of blind children were recognised as having special needs through government provision in India:

*I just could not believe it. After 40 years of independence all the efforts of the government and the NGOs were not able to reach more than 5 per cent. At this school we could take only about 8-10 new pupils each year. We were not even beginning to touch the problem.*

This realisation was the final milestone on the road from charitable concern to strategic action, based on an awareness of the actual size of the problem and its structural causes: he turned the school into a resource centre for training teachers from ordinary schools in how to integrate blind pupils into their classes.

There could not be a more telling testimony to the importance of developing a strategic political consciousness: the result of the change from school to resource centre is that now, with the same budget and the same staff, they reach out to almost the whole of India.

*We motivate ordinary teachers to start services, and they come here for training. So we have made our point and proved ourselves by de-institutionalising. We are infinitely more productive now.*

Political consciousness is not an optional extra ‘for those who feel that way’: if the aim is integration and better services, then there must be a proper understanding of how existing structures marginalise disability and how inadequate the charitable, institution-based approach is. Unless these structural causes are understood, says Father Cutinha, ‘We are still at the level of charity, but simply more sophisticated than before.’

So, in his view, the situation is that the field of disability in India is dominated by both able-bodied and disabled people motivated mainly by charity, and in their own understanding they are doing a reasonable job within that framework. Most disabled people and those who work with them have not reached the stage of consciousness where they really understand the political process. The question therefore is: how can disabled people and those who
work with them become politically aware? Father Cutinha says:

It will happen. We have to build up a consciousness in a small group capable of interacting with a bigger group. They have to discover their own strength and potential before they can interact with the larger issues and a wider group.

As we saw in Chapter 3, the change in consciousness and approach has to begin with disabled people themselves. It is the building of self-awareness and political consciousness in small groups of disabled people in rural areas that forms the substance of the rest of this chapter.

Social action on disability in rural India

On the face of it, the task of trying to deliver services to disabled people in rural India is so daunting that it has not generally been attempted: it is hard enough, it is argued, to deliver services to non-disabled people, so disabled people are off the end of the scale. But the breakthrough comes when it is realised that the medical and institutional model of service provision itself is inappropriate. A model of self-help in which disabled people take responsibility for their own development is required. Furthermore it is not a question of creating extra projects or building new organisations to deal with disability: existing rural development organisations can include disability in their current programmes, especially if those programmes are based on the principle of animation for social action.

It is Action on Disability and Development (India), under the direction of B. Venkatesh (interviewed in Chapter 2), which has been pioneering the concept of integrating social action on disability into existing programmes. In 1988 ADD India persuaded three well-established rural development organisations of very different character, working in Andhra Pradesh and Tamil Nadu, to take on disability in their current programmes. The principle for each was the same: stimulate the formation of disability sanghams (associations) in each village which would assume responsibility for the needs of disabled people in that village. The members of these sanghams would be disabled people themselves.

The three organisations are: the Young India Project (YIP), the Rural Development Trust (RDT), both in Andhra Pradesh, and PREPARE, working in villages around Madras in Tamil Nadu. These three organisations provide contrasting styles and ideologies of rural
development work. It is enough to summarise their approach without offering judgements on their particular philosophies. The important point is that, despite being so different, they all incorporate social action on disability into their existing programmes.

The Young India Project
The Young India Project is an amalgamation of 25 activist groups working in Andhra Pradesh, Karnataka, Tamil Nadu, and Orissa. With an ideology which is mainly Marxist but which also owes a good deal to Gandhi for inspiration on non-violence, it works with the rural poor, especially dalits, to form unions and to press for the implementation of government pro-poor policies through direct action and non-violent mass struggle. It is working to establish 'liberated zones' which are free of atrocities, free of land seizures, and free of police collusion with exploitative practices. It does not believe in and does not run 'development projects' in the way that RDT and PREPARE do: it is an example of a radical social-action organisation committed to struggling for the rights of oppressed people through unionisation and mass action. YIP started working with ADD (India) in 1988 and has now fostered the formation of 44 village disability groups (sanghams) with a total membership of about 1,421 in August 1991.10

The Rural Development Trust
The Rural Development Trust was set up in 1969 and is now an enormous organisation employing over 700 people. It began as a classic project-focused organisation, digging wells and providing help to very poor people, but has now evolved into both service provision and social action. It works in 300 villages in the area around Anantapur with an average population of 2,000 per village; it runs clinics, supplementary schools, and three hospitals. Its cadres of development workers are busy working on literacy, vocational training, community health, and ecological issues such as tree-planting and soil conservation; they also work to establish and animate social action groups of women and landless labourers. RDT's approach to development can perhaps be described as social mobilisation and compassion, in which the provision of services and social action are given equal importance in the total package of integrated rural development. It began social mobilisation of disabled people in 1989, and by the end of 1991 had fostered the establishment of disability groups in 44 villages.
PREPARE
PREPARE was set up in 1983 in response to annual cyclone disasters on the Tamil Nadu coast near Madras. From initially training people to survive, it then began working with tribal people in the area, and later started training villagers in community health. Within the community health programme, immunisation against polio and referral for cataract patients were important features which led to reflection on disability as an issue. The director, Dr Daisy Dhamaraj, says that at the beginning they regarded disability as an individual medical and welfare problem, where immunisation and referral for surgery was the limit of what they saw as necessary. But as their regular development work progressed, they had already begun social mobilisation around women’s issues and the situation of tribal people and fishing communities. They were aware that work with disabled people could not remain at the individual welfare level, but were uncertain how to move matters forward. They looked in vain for models of community-based schemes in self-reliant strategies for disabled people. Then they discovered ADD India in 1988, and PREPARE embarked on the process of social action described below.

In each case the agreement between ADD India and the rural development organisations is that ADD India provides disability training to the organisations’ cadres, carried out in the field and at appropriate institutions such as the Divine Light Trust for the Blind and the Association for the Physically Handicapped, Bangalore. ADD India staff also make regular field visits to give training in social analysis, communication skills, leadership skills, sangham management and administration, and help with planning and evaluation. ADD India has a staff of two field workers, besides Venkatesh, who undertake these tasks. One of them, Saraswadhi, works only with disabled women, in clear recognition that, within disability sanghams, domination by men is a problem.

'The sangham gives me energy and strength'
The rural development organisations provide cadres specifically designated to work on disability, funds raised from their own sources to cover the work, training in animation techniques, and background assistance to disabled people to obtain benefits from the government. The most important part of their work is to encourage the formation of village disability sanghams. In the case of YIP, these sanghams can then become part of regional unions. YIP also provides
training for the disabled members of the agricultural labourers’ union.

The aims of this approach are very clear: to mobilise disabled people to take action on their own behalf, and to use existing structures to secure services and benefits. It was a completely new approach to the disabled people involved; at the beginning they tended to misunderstand what was intended. The charity model prevailed in all minds. When Venkatesh first appeared in a village and gathered the disabled people together, their first reaction was typically, ‘What are you offering? What can you give us?’ His answer was: ‘I am offering nothing. I as a blind person have worked on myself, have found my place in society and can make a contribution. You can too.’ Venkatesh also insisted from the beginning that none of the three umbrella organisations should contribute financially to these sanghams: the sanghams should raise their own money for any expenses, such as bus fares, from their own resources. This was essential to break the expectation of reliance on external agencies.

The idea that disabled people should take charge of their own lives, including their own rehabilitation needs, was completely revolutionary — not only to the disabled people, but also the cadres assigned to work on disability. It takes a long time to train people who are already committed to and skilled in one model of direct intervention to stand back and simply act as a resource and facilitator. In the Young India Project, for example, the person assigned to disability in one area had previous experience as a social worker in another organisation, and saw his new role with disability sanghams as similar: he thought he was required to work on individual cases to ensure that they got the government benefits and services they needed. So he would accompany individual members of the sangham to hospital for operations or to local government offices for loan applications. For him it was stimulating and rewarding to work like this: he could see instant results, the disabled person in each case was very grateful, and he enjoyed a general acclaim in the community as an efficient, persevering, and caring worker. He had spent three years of his life as a wandering ascetic before becoming a social worker, and now felt he was building up spiritual credit for such ‘good work’ with disabled people. But the disabled people themselves were not gaining much in enhanced self-perception or psychological strength through that approach: it was simply delivery of services and a perpetuation of the individual charity model.
The field research for this book included many days sitting in villages in Andhra Pradesh and Tamil Nadu talking to disability sanghams. They ranged in size from half a dozen to 20 members; they included women, children, men, and parents, coping with a wide variety of disabilities. The pattern of replies to questions revealed a substantial change in self-perception and self-confidence. The wounded psyche of disabled people in India can be repaired.

In the village of Dampetla near Penukonda in Andhra Pradesh, the disability sangham has nine members with different impairments: blindness, polio, leprosy, hemiplegia, deafness. Ramu is a 35 year-old woman who contracted leprosy ten years ago; but the disease has stopped progressing as a result of treatment. She is the leader of the sangham and lives on her own with her daughter, aged 8; her husband has left her. She has no land and her 'house' is a palm-leaf hut, probably the poorest dwelling in the village. And yet she has a radiant smile, a strong sense of humour, and a spotless sari. A year ago she applied to the government for a loan to buy a pair of goats. Initially it was refused, but with pressure from the sangham and YIP it was eventually granted. Ramu explains:

By myself I did not have power to persuade the bank to give me a loan for the goats, but when the sangham came in behind me, they eventually agreed. The sangham gives me energy and strength. But it is not only because we can get loans through it: we are more confident in ourselves now. And because we are in a group, the other people in the village respect us more now. Before, we were just forgotten individuals. Now we are people who can do something.

This kind of testimony was repeated in almost every disability group discussion. The tradition of forming sanghams based on other issues is well established: there have been women's sanghams, sanghams of landless labourers, and others for many years, all founded for the same purpose: group solidarity and pressure for social justice in jobs, loans, and land allocation. The fact that disabled people have now formed their own sanghams places them on a similar footing to these others, and attitudes towards them are changing accordingly: they too are seen to be striving for social justice, like everyone else.

Being in such a group also enables disabled individuals to be heard, perhaps for the first time in their lives. Ramu had gained enough confidence through being in the sangham to express herself forcefully in an open meeting on the caste system: 'I am opposed to
it and think it should be abolished. I would like to see an India without a caste system.'

As with other sanghams, it is the lower-caste disabled people who tend to join, because they obviously have reason to. In Dampetla the group reported that there was a blind Brahmin girl in the village, but her father didn’t want her to join. They were sad about this and felt that, given a free choice, she would have joined.

The three young women in Bangalore quoted earlier formed their own independent living centre in order to escape the trap of their over-protective families. Over-protection is possibly the most disabling cultural behaviour pattern in these villages: cases of neglect are rare (although there is no way of assessing the number of disabled infants who are killed or allowed to die). For example, in the village of Mannur near Madras one interviewee was an 18 year-old girl with one arm, whose mother refused to let her do anything in the house, even though she was clearly capable; she had been pulled out of school early and was quietly vegetating at home — a sad waste of human potential. The explanation her mother gave was that she was afraid of what the neighbours would say if she were put to work: she feared they would accuse her of mistreating her daughter. This indeed was the usual explanation for over-protection. But the presence of a disability sangham in the village means that this kind of attitude and practice in families can be challenged.

The most common benefits applied for through the sanghams are loans, reduced-cost bus passes, pensions, and scholarships for school children. The availability of these benefits again places India in a rather different position from most poor countries in the South: it is remarkable that, in a nation of 850 million people, one disabled person in one village can apply for and get a loan from the government to buy a goat. But these benefits tend to be applied selectively, or to applicants who can ‘pay’. Loans tend to be refused on the grounds that a disabled person is ‘not a good risk’; the sangham can play a part there in showing that if the disabled person has sufficient support, he or she is just as good a risk as anybody else. And if a local official is seen to be guilty of corruption, the embarrassment of having a posse of disabled people camped on his doorstep is considerable, and likely to be an effective prod to a decent response. In Dampetla one member of the group is deaf and speaks in sign language, but he has made it his speciality to accompany other members on their forays into officialdom and see that the officials deliver. If they do not, the matter is discussed with the sangham and action taken.
A barber's shop in a village near Anantapur, set up with a loan obtained through the disability sangham.

These experiences of forming a group, lobbying officials, and taking action over their own affairs are themselves greatly empowering for disabled people in Indian villages. They report a new-found confidence in themselves and a new respect from their community. They vividly illustrate the philosophy espoused by Venkatesh and many others, which was discussed in Chapter 3: that a change in attitudes to disability must begin with disabled people breaking out of low self-esteem and forming positive self-images. The vicious circle can be broken, even where the weight of cultural behaviour and attitudes seems at the start to be insuperable.

ADD India has made a significant start on a revolutionary way of working with disabled people in rural India. The costs are extremely low: for ADD India itself, they amount to the salaries and travel expenses of the three field staff; for the rural development organisations the cost is almost negligible, since they use existing staff as animators of the disability groups. That such effective work can be done so cheaply has come as a startling revelation to, for example, the Rural Development Trust: Anne Ferrer, wife of the founder, says:

_Social action is so cheap! For the price of one salary we have seen the formation of groups in 44 villages. Hundreds of disabled people are finding a new purpose in life, and community attitudes are changing._
‘Equality is not created by hand-outs.’
(Yusuf Hiliqawi)

Fact file on the Occupied Territories

*Population*: 1.8 million  
*Religions*: Muslim 90%, Christian 10%  
*Population growth rate*: 3.5% per annum  
*Refugee population*: West Bank 15%; Gaza 60%  
*Adult literacy*: 87% for men, 62% for women  
*Life expectancy*: 60 for men, 64 for women  
*Infant mortality*: 45 deaths per 1,000 live births  
*Annual gross domestic product*: West Bank £686 million; Gaza £243 million

**Background**

Disabled children, especially those with mental disabilities, form a special category in community and social action on disability. In the nature of things it must be their parents and other members of the community who take action on their behalf. This chapter examines the particular issues affecting children with disabilities, and the attempts by their families and the community at large to respond to them within a particular social and political context: that of Palestinian refugees in long-term camps.
In many ways the Palestinian refugee camp context is unique: the problem which gave rise to it certainly has few rivals for intractability. But it obviously has parallels with other refugee situations where people are living in temporary, high-density camps or ghetto-slums without being fully integrated into the host country. Refugee situations give rise to particular problems of development, in particular the problem of how far people can go in taking charge of their own development within a closely circumscribed political context. The reason for considering it in this book is to examine how, even in such very unpromising circumstances, there is the possibility of genuine community action on social issues, and in particular on behalf of disabled children. The implications of this kind of action are far-reaching, having an impact not just on attitudes to disabled people but on the whole psychology of oppression for those involved.

There are some 2.1 million Palestinian refugees living in Lebanon, Syria, Jordan, the West Bank, and the Gaza Strip; nearly 800,000 of them live in camps. Some of them, or their parents, became refugees in the first Arab-Israeli war of 1948; others arrived as refugees as a result of the war of 1967. The ‘camps’ are actually rural or urban slums consisting of densely-packed cement-block dwellings with corrugated tin or asbestos roofs. They have electricity, but sewage disposal is usually via open drains down the middle of the street. Most streets are not paved. There are 61 camps in the five ‘fields’, Palestinian refugee camps have been in existence for more than 40 years. This girl belongs to the third generation born in a camp in Jordan.
with populations that range in size from a few thousand in the small camps to over 100,000 in the largest.

Two years after the Palestinian refugee crisis arose as a result of the 1948 war, a special United Nations agency was created to take care of them: the United Nations Relief and Works Agency for Palestinian Refugees (UNRWA) is mandated every year by the United Nations to provide for the health, education, and welfare needs of these refugees. Unlike any other UN agency, UNRWA has a fully operational role: it runs schools, clinics, hospitals, and other services, and is the largest employer in the Middle East, having a total staff of about 30,000 people and an annual budget of some US$250 million.

The attitude of each host country to these camps is that they are temporary, pending a ‘solution’ to the problem of Israel and Palestine. The camps have always been perceived by the host governments in each country as centres of actual or potential unrest as the refugees find themselves discriminated against in jobs, status, nationality, and opportunity. In consequence the camps are generally heavily controlled, either by the State security apparatus in Jordan and Syria, or by the Israeli military in the West Bank and Gaza Strip. Lebanon is a different case: the camps are on the whole under the control of Palestinians themselves, now watched over by Syria and a reborn Lebanese government, but Palestinians in Lebanon suffer worse discrimination than anywhere else in the region.

There are striking parallels between the overall Palestinian refugee context and the situation of disabled people all over the world. Development (in the sense used in this book) is the process by which people become empowered to take decisions and make choices which affect their lives. Throughout the book we have been examining how that process applies to disabled people, and have stressed that the process of empowerment must begin with a strong sense of positive identity and self-esteem in those who are oppressed. So the development process becomes a quest for how to break out of the vicious circle of oppression resulting in low self-esteem, resulting in victimisation, resulting in further weakness and further oppression. The starting point for change, as we have seen, is self-esteem in the person oppressed. This applies to Palestinian refugees just as much as it does to any other oppressed group, including disabled people.

The Palestinian refugee context also illustrates the problem of what roles should be played by the community on one hand and the State on the other. In this case, the State role is taken by UNRWA, which
provides most of the services that one would normally expect from a government. UNRWA was set up primarily as a relief organisation and a provider of basic services. Some people who work in it see its role as limited to that function, but an increasing number point out that its title contains the word 'Works' as well as 'Relief', and that its mandate does imply a developmental role. This argument is conducted with particular intensity over disability and what role the agency should play in providing services for disabled people.

The issue of 'community' in the Palestinian camp situation also brings into sharp focus the question of who controls the development process in a highly charged political environment. Over the years three layers of service provision and development activity have emerged in these camps: first, there is UNRWA, which provides the basic neutral infrastructure for people to live, get educated, and stay reasonably healthy; second, the provision of services is a key part of the struggle for the hearts and minds of camp dwellers, and thus 'development' becomes a tool in the hands of Palestinian political factions vying for influence, territory, and credibility; third, there are efforts outside either of these first two to set up development activities by foreign NGOs and non-aligned local groups and individuals.

In the minds of most camp Palestinians there is a high degree of ambivalence about the role of UNRWA. On the one hand, the agency stands as a symbol of their refugee status, and they regard the services it provides as a minimal right in the face of the injustice of being made refugees in the first place. On the other hand, they readily agree that UNRWA, by concentrating on relief and not development, has, over the forty years of its existence, created a 'hand-out' mentality that has undermined the spirit of initiative and self-development, and done considerable damage to the collective self-esteem of the refugees. UNRWA itself, recognising this dilemma, has made efforts over the past ten years to play a more developmental role by encouraging income-generating projects aimed at individual self-sufficiency. Its approach to disability has also been conducted in the spirit of development rather than relief, as we will see below.

This scenario applies to each of the five fields in which UNRWA operates: Lebanon, Syria, Jordan, the West Bank, and the Gaza Strip. This chapter focuses only on Jordan, the West Bank, and Gaza, which have certain specific conditions of their own. In Jordan the camps are kept under very tight surveillance by the State security
apparatus, and any community activity is closely watched. The formation of a local committee requires a list of names to be submitted to the Jordanian security department, which routinely rejects those it does not approve of. But there is a ‘Catch 22’ here: without a properly registered charitable society with its own officially approved board, it is illegal to raise or receive donations from any quarter, either local or foreign. This clearly acts as a severe restraint on properly organised community action.

In the West Bank and Gaza Strip a similar situation prevails, but the surveillance is of a different kind, because there is a clear dividing line between Palestinians and the Israeli military; in other words, Palestinians fall clearly on one side of a political divide, whereas in Jordan the line is not so clear: in Jordan Palestinians are part of the government as well as the governed, and so the form of control is more subtle than it is across the river.

The contrast in control systems was dramatically illustrated for me recently on visits to camps on both sides of the river: while visiting a community disability centre in Jabaliya Camp in the Gaza Strip, I witnessed a classic battle between Israeli soldiers with rifles and children with stones just outside the centre itself. An Israeli soldier was hit in the face by a stone, and a boy from the camp was hit in the head by a bullet; he later died. In Jordan a few days later on a visit to a similar centre, I was shadowed by a State security agent who I thought at first was a parent, and who insisted on sitting in on a local committee meeting.

Such control mechanisms, whether by brute military force or subtle infiltration, make these camps far from ideal places in which to embark on the process of community development, but there are strong counterbalancing factors. In particular there is a heightened sense of communal and national consciousness, and thus an enhanced willingness to work for the common good. The history of development in the West Bank and Gaza Strip reveals, since 1967, a process in which people, both in camps and in the community at large, have increasingly managed to shed the role of passive recipients of aid and take charge of their own activities. There has been a growing realisation that nothing can be gained by waiting for peace to arrive before beginning development, and that the peace process is more likely to succeed if there is some equality between the parties; but equality is not created by hand-outs. Consequently there was a phenomenal growth of home-grown development efforts during the 1980s, to promote such activities as pre-school
education, agriculture, health care, and women's groups. The Intifada (Uprising) that erupted in late 1987 was a result of this new assertiveness and self-confidence, and also served to develop it.

The parallels with the situation of disabled people everywhere are only too clear: breaking the vicious circle of oppression entails refusing to play the role of victim.

**Disability in the West Bank and Gaza Strip**

The situation for disabled people in the West Bank and Gaza Strip is an illustration of outdated concepts dominated by professionals and those involved in a major rehabilitation industry. There has for a long time been institutional care available for some (but by no means all) disabled people; however, these institutions have been strongly characterised by the 'charity' model, and the removal of disabled people from their own environments. Some of these institutions have tended to operate behind closed doors, with a reluctance by their staff even to co-operate with surveys or to allow access by researchers to their disabled 'inmates'.

Although there have been a few attempts to introduce CBR (Community-Based Rehabilitation) in some form in some areas, the general attitude towards disability among people and groups working in development up to the mid-1980s was that it was not a priority, and that it was part of welfare rather than development. Developmental priorities were concerned with the establishment of basic services in primary health care, agricultural extension, women's activities, and early childhood education. Disabled people were generally either ignored or confined out of sight in institutions.

But with the advent of the Intifada in December 1987, there was a sudden explosion of interest in disability: it became politically important. Confrontations between young people with stones and soldiers with rifles produced a dramatic increase in permanent impairments such as spinal-cord injuries, loss of eyes, and amputations. The injured were regarded as heroes and the whole 'industry' of rehabilitation received a dramatic boost. Millions of foreign dollars were poured into creating large and extremely well-equipped rehabilitation centres, but without thinking of needs beyond the medical, and without being able to construct an interconnected referral system of which these centres were a part. In addition the needs of other disabled people, not the 'Intifada-injured', who formed by far the largest proportion, were eclipsed.

This failure was caused partly by the fact that there is no
Palestinian government and therefore no central planning authority, and partly by a concept of rehabilitation and an approach to disability which is almost entirely medical. The political dimension, in so far as the 'Intifada-injured' were disabled in a political struggle, did nothing to alter this perception; in fact it enhanced it. The failure was as much the fault of foreign funders as anybody else's. The Swedish government, for example, provided millions of dollars for an extremely well-equipped rehabilitation centre in Ramallah, which at the time of writing has only ten beds filled. The same sum would have been enough to fund dozens of neighbourhood rehabilitation centres for years.

The testimony of many of those injured is that medical rehabilitation, despite its undoubted quality, has not addressed their real needs. The sense of heroism soon wears off after the initial visits by well-wishers to the hospital and after the injured person arrives home to find that he or she is an economic burden on an already hard-pressed household and, furthermore, is doomed to spend the rest of his or her life doing absolutely nothing.

For example, Nihad Mansour, who lives in Jabaliya refugee camp in the Gaza Strip, is now paralysed from the waist down after being shot in the back by an army patrol:

*I had treatment and rehabilitation in various places. I spent a while in the Abu Raya institution in Ramallah, which was nice and very well equipped, but when they had finished with me, they just sent me home. There was no attempt to provide me with training or to plan for my life as a paraplegic, or even to counsel me on what would be involved. Their approach was purely medical. What's the use of that? I knew people in the Abu Raya centre who made sure that their bedsores did not heal so that they would not be sent home.*

The real needs of a paraplegic like Nihad begin when he gets home, not when he is receiving treatment.

The interest in disability created by the Intifada was not, after all, a change in attitude, but simply a perpetuation of the old attitudes, with more attention and more money. As we have already seen in Chapter 3, it is of no service to disabled people to regard them as heroes; they need to be treated like anybody else, rather than placed on a meaningless pedestal. At no point have disabled people themselves in the West Bank and Gaza Strip played a role in the process of designing services or planning strategies; the national committee on disability, formed in 1990, contains not a single
disabled member, and none of the main institutions has any disabled members on its board.

The control over policy and resources for disability in the West Bank and Gaza Strip is firmly in the hands of professionals and those with a stake in the rehabilitation industry. There is an urgent need for disabled people to be included in the planning process, precisely to deal with the kinds of problems faced by Nihad and many others. At present there is an unseemly willingness to make political and financial capital out of the Intifada-injured without understanding or catering for their real needs, or involving them in planning as people with needs beyond the medical, and with experience that could be tapped.

Why has there been no mobilisation of disabled people in the West Bank and Gaza Strip? In a society where political consciousness is so highly developed, this lack is (on the face of it) surprising: it is particularly surprising because people injured in the Intifada, regarded as heroes, generally escape the stigma that usually attaches to disablement. There seem to be a number of reasons for this failure to mobilise.

First, most grassroots activity tends to be undertaken in the name of one Palestinian political faction or another, and it is not at all easy for spontaneous activity to avoid being patronised in this way. There is a genuine ‘popular movement’ but it is fragmented between at least five factions, four political and one religious.

Second, moving around in these territories is extremely difficult, even for non-disabled people: there are continual curfews and roadblocks; going to Jerusalem, a central point, requires special permission, and being allowed to leave the Gaza Strip for anything other than casual labour inside Israel is rare. Hence building an organisation of any kind has very practical, logistical obstacles.

Third, because it is hard for people to travel, links with and knowledge of other models are slight. Hence thinking on disability in the West Bank and Gaza Strip, among both disabled people themselves and those relating to the issue, remains at present stuck in the format that relies on professional rehabilitation and charitable institutions.

Fourth, the formation of groups run by disabled people implies, in the minds of many disabled people, that there is a State authority from which such a group can make demands. Where that does not exist, there is much less incentive to form such groups. Ibrahim Tilbani, now in his forties, lives in Jabaliya camp in Gaza and was
blinded as a child; he is the head of the local disability committee and has given thought to the question of forming a blind union; but, as he observes:

_It comes down to the question of a government, or the absence of a government. If you have one, it can create laws and regulate society. In the absence of a law, nothing can happen. In Gaza there are workshops and things like that which employ blind people, and I could set up a union of blind people tomorrow, but my question is, ‘What would it offer me?’_

Another disability committee member, Yusuf Hiliqawi, agrees:

_Consider: who shall we demand our rights from? What body will give disabled people their rights? There is no body here to award rights under the law._

However, as we will see in the case of Lebanon, the absence of a law-giving authority does not mean that disabled people cannot or should not mobilise; indeed rather the contrary, since disabled people can add a very important dimension to the whole discourse about civil and human rights. In Lebanon, despite the virtual absence of a government for fifteen years, disabled people have mobilised to considerable effect, especially against the war and the absence of rights for disabled people — which includes the absence of a government to give those rights. A peace march by disabled people in Jerusalem would be a very powerful expression of a desire for and commitment to peace and social justice.

In Jordan the overall situation in disability is similar, with a fairly high-tech rehabilitation industry attracting large funds, especially from wealthy individuals, and a focus on institutional care, especially for children. But there are important differences from conditions prevailing in the West Bank and Gaza Strip. In the first place there is a government which has made a commitment, through legislation, to creating opportunities for disabled people. Secondly, groups of disabled people have started to form in Jordan. However, we are concerned here not with Jordan as a whole, but with the refugee camps which form a separate community under different constraints; these constraints ironically make effective local mobilisation even more difficult than it is in the West Bank and Gaza Strip. Confrontations with the Israeli army in camp communities west of the river have a strong unifying effect and provide a powerful incentive to undertake community action in the
teeth of such difficulties. But where the control is more subtle, there
is less incentive.

However, it was in the Jordanian camps in the early 1980s that
the seeds of a new approach to disability were sown which are now
bearing fruit in Jordan, the West Bank, and Gaza Strip: the
mobilisation of whole camp communities to deal with the issue of
disabled children.

Community mobilisation and disabled children

In 1981 UNRWA decided, in the light of the International Year of
Disabled Persons, to ‘do something for disabled refugees’. It
proposed the setting up of a low-cost community centre for disabled
children in one smallish rural camp in Jordan, Suf, with a population
at that time of 11,000. A house-to-house survey was conducted
which revealed a population of about 150 disabled people in the
camp, of all ages and disabilities. Of these, 40 children with mental
disabilities were seen as needing specialised services. An old tin
building was renovated by the local youth club, two women from
the camp were given basic ‘training’ for a month at an institution in
Amman, and the first Community Rehabilitation Centre (CRC) in
these camps was born.

The central objective was to provide a basic service and to change
attitudes to disabled people within the community. The concept was
to keep costs low, to involve the community through a local
committee and the use of volunteers, and to provide a non-
professional day service for those who could benefit from it. As far as
the usual rules of community development went, it broke the most
basic: the initiative came from the outside (indeed very early meetings
with camp elders produced the response, ‘We don’t have a problem
with disability here’), and UNRWA provided the administrative
support. Running costs came from a European funding agency
(Oxfam/UK and Ireland). Understanding about disability issues was
minimal at the beginning in all three parties: UNRWA, the European
funder, and the local community. But despite these apparent
drawbacks and the undeniably amateurish way in which the whole
thing was approached at the beginning, it was the start of a learning
process between these three parties which, ten years later, had
prepared the ground to shape a policy on disability for the refugee
population for which UNRWA is responsible.

The story that has unfolded since 1981 illustrates many valuable
lessons in the development process, especially as it relates to
disability. Because of its hidden nature and the stigma that it carries, disability has not been an issue around which these refugee communities (or any other communities for that matter) have naturally mobilised. The response of the elders in Suf, denying that disability was even a problem, is not unusual. So an outside initiative was justified: there needs to be a trigger for community mobilisation, and in this case it was provided by UNRWA.

Once the centre in Suf had been opened, attitudes did indeed change dramatically: the pessimists had said before its opening that people would not be prepared to bring their children to the centre, because they would not want it generally known that they had a disabled child, especially if the disability was mental. They told stories of mentally disabled children being kept chained to a bed in a dark room. But it turned out that such stories, if true, were not at all typical, and that parents for the most part were desperate for some help with their children — help which the centre was now able to provide. They flocked to the centre. Children appeared who had not been detected in the initial survey, testifying perhaps to the 'dark room syndrome' but also to the desire of their parents to remedy the situation.

Other camps took note. The foundation of the Suf centre sparked within a few years the establishment of four other centres in camps in Jordan, supported by different foreign NGOs and administered by UNRWA. Attitudes in UNRWA changed too. In 1989 UNRWA decided to establish the posts of Disability Programme Officers in all five fields; these DPOs would be responsible for instigating community action on disability in the refugee populations of their respective fields. This was a major shift in UNRWA: it was a clear indication that the agency was now taking disability seriously.

But there were important points of principle which had not been sorted out. The most crucial were:

- Who owns these centres: UNRWA or the community?
- What role could local committees play in running the centres?
- Should the centres rely entirely on volunteers? Should the volunteers be paid anything — and, if so, how much?
- How 'professional' should the services be? To what level should the volunteers be trained?
- What about provision for disabled people who did not attend the centres?
- What would happen to children once they had left the centres?

In Jordan there were real difficulties in forming local committees, for
the reasons stated earlier: all names had to be approved by the security authorities, which cut out more or less everyone except the most conservative and ineffective. Early committees were soon disbanded. So the centres in Jordan have remained in a kind of limbo, with no real control by the community at all, under the UNRWA flag but not recognised as part of UNRWA's essential services.

Top-down control or bottom-up development?
Across the river in the West Bank and Gaza, however, there was the opportunity to approach the task differently, and also to break with the usual heavy emphasis on institutional care dominated by disability industry magnates. Abdul Qadir Awad, the DPO for the West Bank, perceived from the beginning that the key to constructive community action on disability lay in the formation of an effective local committee, and that his role was the establishment and support of these committees. He describes how he set about the task of forming local disability committees:

> From the outside it is important to identify those who have some influence in the community. Then you have to look at what already exists in the camp or community in the way of associations and bodies which are doing things. It is important to assess how effective they are. Once you have assessed who the effective people are, you can enter the community through them. Through them I can get to know others. The most important thing is to choose people who have a good reputation in the community and who are effective.

What is his own role once the committee has been formed?

> I don't want to put all the responsibility on the local committee, nor do I want to put it on myself. It must be shared and balanced. The local committee needs to be the main entrance to the disabled people in that community for any organisation that wants to deal with them. They have to have the power to make decisions. That is very important. Most programmes in the Occupied Territories are run from the top down. We want this to be bottom up.

Secondly, they must have the freedom to shape the programme as they see fit. They know the needs of the community much better than I do. My role is advisory on the professional level. I can advise on technicalities. I can also help them with funding; that's very important. I am a facilitator in the programme, not an implementer.
My third very important role is to open them to other experiences, both in the Occupied Territories and beyond. This society is very closed. People do not know about what is going on elsewhere; they need to be told and shown.

By late 1992 there were eleven committees in West Bank camps and four in Gaza. Ahmad Amaasi, a member of the Fawwar camp disability committee, describes how they got started:

We formed a local committee and started to work on the issue of disability. The first thing we did was undertake a survey. The total number of people in the camp is about 4,000. We used volunteers from the camp to do the survey. We divided them and the camp up into groups. We went house to house, every house. We found 366 cases of different disabilities of all ages. Our definition was as wide as possible: we included, for example, asthma cases.

We arranged for those with mobility problems to see specialists in hospitals and get aids and appliances and physiotherapy. We tried to arrange for hearing aids for deaf children, but they are very expensive. We realised that there was a small number of children, about 15, who would benefit from the opening of a centre. These were mainly children with cerebral palsy, and mental disabilities.

We first thought of building or renovating a building, but could not get any funding for it, so that idea had to be cancelled. But the youth centre was not being used, so we decided to use that, at least temporarily. There was no glass in the windows, the place was a mess, so there was a lot of work to be done.

Well, we started by collecting money from people locally, from the zakat [religious tithing system], for example; we bought some furniture and some toys. We opened the centre at the beginning of this academic year, in September. It is equipped with basic furniture and also a small kitchen where we can make sandwiches for the children.

All this has been done in Fawwar without any external funding. In Jabaliya camp in Gaza there was a similar process. A committee was formed, and UNRWA made available an old, derelict building once used as a supplementary feeding centre. The committee began to collect individual donations from the camp community: a receipt book recording local donations revealed a remarkable story of interest and enthusiasm: ‘Hassan Shqeir — one bag of cement; Ibrahim Bseiso — ten shekels; Fatima Murad — fifteen shekels;
A volunteer from Jabalia refugee camp in the Gaza Strip prepares a door for the community disability centre.

Muhammed Musa — 20 cement blocks; Ahmad Nasrallah — five sheets of corrugated iron ... and so on.

Within a few months of the committee’s formation, the derelict building had been transformed into a smart centre with three classrooms, freshly plastered and painted. As in Fawwar, the committee had already done a survey of Jabaliya, a very much larger camp containing about 60,000 people. Tammam Ashqar is the only woman member of the Jabaliya disability committee:

The survey came up with 1,800 people with disabilities in the camp out of a population of 60,000. Of these, 70 were deaf children. Then we thought, which group of disabled children is not served in the Strip at all? We realised it was the deaf: there is no institution for the deaf in Gaza. This is the most difficult group to deal with here, because there is nobody with experience in teaching them. But so far we have made good progress, and many of the children have started to acquire some speech. We are pleased with what we have done.

To start with, we accepted 24 in two classes, and we are now planning to open a third class with a further 12. Eventually we hope to absorb all the deaf in the camp.
Voluntarism versus professionalism
So far, so good. But the question of expertise immediately comes to the fore. All these centres have started with volunteers who have had minimal training, or none at all, in any form of special education. Such an 'amateur' approach has received fierce criticism from people running 'professional' institutions, who argue that if teaching non-disabled children requires trained teachers, how much more important is it to have well-trained specialists working with disabled children? Can untrained volunteers do any more than just keep the children occupied? If boredom sets in because the teachers do not know what to do, the whole concept of a rehabilitation centre is undermined.

This is an extremely important question which has enormous implications for any community action on disability. Working with mentally disabled children in particular requires higher than average levels of creativity, imagination, and understanding of child development. The experience of the centres so far, since the one in Suf first opened in 1983, has been that raw volunteers from the camp, with no previous experience or training, can reach more than satisfactory levels of expertise through their own experience, reinforced by regular training inputs by specialists. In the Jordan programme several in-service training experiences have been arranged over the years which have, to varying degrees, transformed perceptions and expertise.

In the early days of the Suf centre, mentally disabled children were sat in rows in desks in front of a blackboard, while the teacher struggled to work through a curriculum that was taken straight from a primary school: that was the only kind of 'teaching' which the volunteers themselves had ever experienced. But gradually, with input from specialists and especially those who opened windows on to discovery learning and tapping inner sources of creativity, the volunteers have acquired skills which make many of them now the equal of (or superior to) trained teachers in better-equipped and better-funded private institutions.

But this increasing expertise in the volunteers has raised another fundamental issue. Many of them can now legitimately claim to have impressive skills, and they feel that they should be duly rewarded. Are the centres not exploiting them by using them as volunteers for either no pay or very low honoraria? Is this not another case where disability and indeed women — since nearly all the staff are women — are being given a raw deal yet again.
This matter has a bearing not only on the quality of work being done in the centres, but also on their sustainability: it is one thing to collect donations from a refugee community, where unemployment usually runs as high as 40 per cent, for bags of cement and roofing materials and small cash contributions to renovate an old building. It is quite another to expect the same community to support a system where the staff are being paid proper salaries. Should foreign agencies pick up the tab, or, in the case of these centres, UNRWA itself? It brings us back to the role of the State versus the role of the community, the role of the State in this case being taken by UNRWA. Somehow a balance has to be struck between service provision by UNRWA which does not involve the community and which therefore perpetuates the ‘hand-out’ mentality, and a truly vigorous local initiative whose survival is precarious.

There is also the question of where disability fits into the planning and thinking of governments or government surrogates like UNRWA. It may be legitimate to ask why disability should be relegated to low-key, unofficial community initiatives relying on low-paid volunteers when the regular school system, for example, is properly funded with paid and trained teachers.

On the other hand, there has been a marked change in consciousness within UNRWA, generated by the establishment of these centres among other factors, which was noted by many of those interviewed, for example As'ad Daud, a blind person from Ain el Hilweh camp in Lebanon:

It's extraordinary what has happened inside UNRWA over the past few years in terms of disability. Now you can sit with UNRWA people and talk about it, and they understand. Five years ago they would not even have been prepared to listen to you. There is a new climate; people are interested and knowledgeable.

This new awareness has created a willingness among the educationists, for example, to discuss integration, a willingness that was not present ten years ago. Integration into normal schools for those who can be integrated is now an increasing reality for numbers of disabled children in these camps.

But it is not a question of whether UNRWA should take sole responsibility for these centres; it is not either UNRWA or the community: there can be real partnership between the two. It is possible, certainly in the situation we are dealing with here, to have vigorous local initiative with long-term sustainability and high
standards. Clearly community participation and ‘ownership’ of such services is an immensely valuable prize, not just because there is a greater sense of empowerment for the people concerned, but also because the service is more likely to be effective, human, and appropriate. It would be an entirely retrograde step to operate these centres on the same basis as the schools, in which there is no community participation and little attempt to cater for the needs of the individual child. But at the same time, UNRWA has an outright obligation to see that disabled children have the same chances as any others, and it can fulfil this responsibility by ensuring the financial sustainability of local initiatives, just as governments do in other countries, including Lebanon. A government subsidy does not mean government control.

Beyond the centres
There remains the challenge of those who do not attend the centres, and the question of what happens to the children when they leave the centres. There are also other fundamental problems, in particular the lack of both women and disabled people on the local committees in numbers that could be considered significant.

The danger of opening a centre is that the efforts of the local committee become focused on it to the exclusion of other responsibilities. We have seen that in Jabaliya camp, for example, the centre is at present dealing with only 24 children out of a total population of 1,800 disabled people. There are many other things to be done: home visits, provision of appliances, modifying houses to make them accessible, raising awareness, improving health and transport services, integration into mainstream education. The committee is responsible for these and anything else relating to disabled people and their needs. The establishment of a centre was not the first thing which the committee in Fawwar thought of or undertook. Ahmad Amaasi explains:

Besides the centre we also have a programme for helping slow learners in normal school. Forty students in the regular school are being given supplementary lessons, a very important activity. This programme runs after school. We focus mainly on Arabic and arithmetic. But the teachers doing this have received no payment either.

In activities outside the centre we have installed toilets in the regular school which can be used by people in wheelchairs. We are also working with families who do not send their children to the centre. We
arrange transport for disabled people who need to go to hospital, for x-rays, for example. So there are three programmes at present: in homes, at the school, and in the centre.

These activities too have been supported by contributions from the camp population. Abdul Qadir, Disability Programme Officer in the West Bank, illustrates:

The Fawwar committee sent me a note saying how much the community had contributed: 500 shekels as a contribution towards running the centre, 500 for food, 850 shekels for furnishing the centre, 700 shekels for training and for transporting the trainees. That all adds up to 3,400 shekels (£618) from the local community.

Jenin the same: they rented a place for 700 dinars (£700) a year; 17 dinars for transporting a disabled person from his home to the institution for computer studies where he is studying; 80 dinars for x-rays; cassettes for 20 dinars; 23 dinars for stationery.

These little things all add up to an effective approach which builds trust among people in the community. The local committee opens doors into the rest of the community. For example, in Jenin there is a merchant who donates 50 dinars every month to the committee.

Another gives 70 dinars per month towards aids and equipment. People realise that the local committee is much more in touch with the needs of disabled people than anybody in Jerusalem, and they can see to them properly.

The aim of the committee is to reach the biggest number of disabled people possible. They do that partly through the centre, but also through other activities.

The issue of what happens to children after they have left the centres remains the single biggest unsolved question. There is an absolute need for vocational training and possibly for sheltered workshops for those who cannot live independently. But no real steps have been taken in this direction, perhaps because the whole enterprise seems too big for the rather low-key and low-cost approach that has been the main characteristic so far, and also because there is a very high unemployment rate anyway. But it cannot be left unaddressed.

Lessons from the Palestinian experience
Some development workers consider that community mobilisation and participation 'is only possible when the community has reached
a certain threshold in economic, social and educational awareness'. This seems a very curious approach to community development and, if accepted, it presumably rules out a large number of communities in developing countries from even starting on their own development, because it assumes that some have passed the threshold and some have not; and in any case, who is to decide when a community has reached that threshold?

The story of community action for and with disabled children in the Palestinian context gives the lie to such an idea. The local initiatives in disability described in this chapter are a clear demonstration that, even in the most difficult economic and political circumstances, community mobilisation and full participation are possible. Indeed, the story of these efforts illustrates that the process of acquiring social awareness occurs when people themselves take positive action for change despite all the obstacles, without waiting for the economic or political situation to improve. It is yet another example of change having to start with the oppressed.
Lebanon: rebuilding civic consciousness

'Is this all? Just rehabilitation exercises, and eating and sleep? Isn't there anything else?'
(Hassan Bsat)

Fact file
(Note: these figures are even more approximate than most statistics: there has been no national census in Lebanon since 1947.)

Population: 3.3 million
Religions: Christian and Muslim in approximately equal proportions. The exact balance is subject to debate. There are also sects within the major religions (for example, Sunni, Shi'ite, and Druze Muslims) which are an important aspect of the confessional mosaic of Lebanon.
Languages: Arabic; English and French are also widely spoken, and Armenian among the Armenian population (5% of the whole).
Population growth rate: 1.1% per annum
Refugee population: 300,000 Palestinian refugees. There were probably at least one million internally displaced people at the height of the war.
Urban population: 80%
Life expectancy: 65 for men, 70 for women
Infant mortality: 50 deaths per 1,000 live births
Annual gross national product: £1,273 million
Annual GNP per capita: £378.00
Sister Sonia is a nun who has worked all her life with mentally impaired children. Until February 1991 her life was the special school which she ran in the mountains above Beirut in an old monastery on the edge of the village of Qalʿa. It overlooks a deep, wooded valley reaching down to the Mediterranean 3,000 feet below, a magical — and strategic — spot.

Then the shells came, from three directions, for 48 hours without stopping, without giving the children a chance to get out. Every room was destroyed. Gaping holes were smashed in the cut stone walls; the roof fell in; the beautiful building with its arches and vaulting which had watched over the valley for more than three hundred years was reduced to a ruin. Miraculously no one was killed. By an extraordinary piece of luck, Sister Sonia found a secret passageway under the kitchen floor, an opening to a flight of steps which had been tiled over and hidden by a chest; the steps led down into a small chamber below ground level, where everybody in the building, staff and children, huddled as the explosions thudded and roared above them and the foundations shook.

On a recent visit Sister Sonia showed me the secret passageway, and upstairs the shattered rooms where the children had slept, now deep in debris from collapsed walls and roof; the occasional sodden blanket and decapitated dolly peeped from under the rubble, the only signs that this had once been a place alive with children's laughter.

Within two months of being bombed out of this magnificent building, Sister Sonia had set up the school in another building in a nearby village.

**Background**

Lebanon has paid the price for being, once, the freest state in the Middle East. Here was the heart of intellectual liberalism in the Arab world, where the press was free, books were published without censorship, and the universities produced creative and seminal thinkers. But it was — and is — also the cockpit where the different ideologies and power interests of the Middle East and the world at large clash. Add to this gross inequalities in the social, economic, and political life of the country, and the scene was set, in the early 1970s, for the wrecking of what was once a unique and beautiful country, often then referred to as the 'Switzerland of the Middle East'.

Outsiders now perceive Lebanon as a place of unrestrained and incomprehensible violence, of war which has long since lost sight of
its original aims and which defies analysis. But that sensationalised and over-simplified image is far from being the whole story. There is also a story of individual and collective courage that struggles against the chaos to create and maintain an alternative based on co-operation and civic consciousness.

In the mid-1970s Lebanon had a population of about three million. Since the beginning of the war in 1975, 144,240 people have been killed, 197,506 injured, and 17,415 listed as missing, presumed dead. Hundreds of thousands have been displaced. The number of people disabled by the war has never been counted. The Lebanese pound exchanged at four to the US dollar at the start of the war in 1975. The exchange rate in September 1992 was about 2,000 to the dollar.

The war is officially over, the militias mostly disarmed. The Taif Agreement of 1991 which ended it gives Muslims one more seat in a cabinet balanced precariously across the sects. The ‘global’ war, representing the clash of Middle Eastern and world power interests fought out by proxy in Lebanon, is perhaps over for the time being, with the end of the Cold War, the neutralising of Iraq, and the redrawing of the political map of the Middle East. But in south Lebanon the Arab-Israeli war rumbles on, as intractable as ever.

*Sister Sonia in the ruins of her centre for disabled children. Fifteen years of civil war have come to an end. Now the task of building the peace is immense.*
Fifteen years of civil war have left scars which will take decades to heal. A whole generation of children has grown up knowing nothing but war, with their education severely disrupted or largely absent. The fracture lines in Lebanese society remain, and it will take a long time before trust and confidence across these lines are regenerated. For fifteen years there was virtually no central government authority, and scant respect for the rule of law. The political process has been largely discredited. The task of building a democratic, civil society from this base seems, to say the least, daunting.

Disabled people have already started, however, to make a significant contribution towards rebuilding civic consciousness. The disability movement in Lebanon, the most vigorous in the Middle East, makes its claim to be part of a constructive and positive culture, creating a consciousness that is against violence, against the sectarian divide, and for the development of human potential.

Disability in Lebanon

In war situations in particular, disability is perceived as a medical problem. Funding for medical rehabilitation, which does not address the long-term or social needs of disabled people, is the easiest to obtain. The war disabled thousands of people in Lebanon and also created the general sense that 'we must do something about disability'. But this sense, instead of leading to a cool appraisal and an accurate assessment of the overall picture based on a real understanding of the needs of disabled people, resulted in the funding of expensive medical rehabilitation centres within the sectarian framework. Nawaf Kabbara, paralysed in a car accident in 1980 and now president of the Friends of the Handicapped in Tripoli, observes:

_This emphasis only on medical rehabilitation is exactly the opposite of what is needed. That's why this sense of 'We must do something for disability' is very dangerous. Instead of using what could actually be positive in terms of reaction and good will, it is turning out to be our prison. 'Rehabilitation' has become an industry based on the medical model which has not addressed the real situation of disabled people at all in terms of their rights and long-term needs. It has only served to reinforce the trap that we are in._

There is also the question of how disabled people are perceived in Lebanese society as a result of the war: has the increase in the number of disabled people created a new awareness and better understanding? Muhammed Halabi, a member of the Lebanese Sitting
Handicapped Association in Sidon, sums up attitudes as follows:

There are three ways in which people relate to disability and disabled people: some people are aware, but very few of them; these are usually people who have some personal experience, but not all those who have personal experience are aware. There are other people who regard you with pity, who say, 'God cure you' when they see you; these people do not allow you to contribute or to give of yourself. There is a third sort who simply ignore you; they just do not take any interest in you at all, they are embarrassed, they treat you as though you are not even part of society. These are the majority.

Personally I have the following experience. Education? I got educated. Employment? I got employed. With a great deal of effort a disabled person can achieve these things. There is just one thing that I have not been able to do, and that is to get married. This is the clearest indication that disability is not acceptable in this society. People accept you as a teacher or a pupil, or as an employee; but, as a brother-in-law or a sister-in-law, that's something else. That's where I am. It's a very important point.

Muhammed Halabi, a teacher of computing. 'People accept you as a teacher or a pupil, but not as a brother-in-law.'
Attitudes to disabled people, in other words, are pretty much the same now as they were before the war. As should by now be abundantly clear, just providing medical rehabilitation services does not amount to a positive attitude towards disabled people. One of the central themes of this book is that disabled people have to take the initiative in changing attitudes, starting with themselves, because if they don't do it, no one else will. In Lebanon this task has taken on a particular dimension because of the war and the circumstances that created it, and the stupendous task of trying to build a society that will not easily revert to the grinding attrition of the last fifteen years. This requires, in a word, the building of a civil society, which means a society which functions by the rule of law, by principle rather than private interest, by a civic consciousness which has a vision of the common good, and by tolerance of ideological and religious differences.

What has this got to do with disability? Simply this, that the disability movement in Lebanon is committed to addressing these problems both within itself and within the country as a whole. These are problems that affect everyone, not just disabled people. But a solution will not be found until the problems have been defined and a commitment made to building a culture that opposes their causes. The situation of disabled people and the disability movement provides a visible and tangible model that can illuminate the problems and act as a laboratory for doing things differently.

For example, many people working now for these aims in Lebanon, especially in the disability movement, point to the problem of individualism as one of the main obstacles to the creation of a civil society: things get done and jobs secured through personal contacts and favours, rather than through a system based on rights or objective principles. This feature, known as *wasta* in the Middle East, is present in all societies to some degree; but, where it is the norm rather than the exception, it makes the raising of serious issues and matters of principle highly problematic or downright impossible.

Nada Azzaz, a blind person living independently on her own on a tenth-floor flat in Tripoli and an active member of Friends of the Handicapped, explains the problem like this:

*The State is absent in Lebanon. Everything the State should do is done by individual initiative. A few disabled people have got jobs with the government, but they have got them as favours because of personal*
contacts, and they are not necessarily secure in these jobs; they have them on sufferance, as it were.

The problem is exacerbated, as far as jobs are concerned, by Lebanese law, which, as Nada points out:

... explicitly discriminates against disabled people: the law states that no one can be employed by the government who is not physically fit and 'free from deformities and defects'.

Despite this law, it has been a tradition for some time in Lebanon that blind people can work as telephone operators in banks and government departments. But, as Mu'nis Abdel Wahhab, another blind person from Tripoli, points out:

This is done on the basis of pity, not rights. These people have no job security, they are not properly integrated into the employment system; they can be dismissed at any time and have no pension rights, for example.

For As'ad Daud, also blind, from the Ain el Hilweh Palestinian refugee camp near Sidon, jobs by right are the key to a change in consciousness throughout the whole of society:

I was just crossing the road now on the way to this interview and a girl tried to give me money instead of helping me to cross the road. She thought I was a beggar. How should I react to that? Lecturing this girl is not going to make any difference. What will make a difference is when blind people can have jobs like everyone else. Even if I lectured this girl for three hours and then she goes out and sees a disabled person begging in the street, what is the point of the lecture? But if she saw me working, she would understand.

You cannot give disabled people their rights by giving them money. Money does not give anybody their rights. I cannot solve the problems of a disabled person by giving him 3 million dollars. That amount of money does not defend him. What defends him is his job, his work. If he has a job, he is living proof that he is a human being like everyone else.

But we disabled people have to change, in the sense that in whatever field — shaving, crossing the road, going from place to place — one has to depend on oneself to the greatest extent possible. This society has to respond to the new century and show that it can treat disabled people as full human beings, and disabled people also have to respond to the changes and work hard to get jobs.
So building the peace means building a civil society where issues are placed above personal interests. But unless there is a commitment by the government to giving legal rights to disabled people, there is little hope of creating major changes in perceptions and attitudes throughout society. At present discrimination is enshrined in the law, with apparently no accessible mechanism for correcting it: the politicians have other priorities, and disability does not swing votes. What to do?

Across the world the movement towards civil and social rights has to focus on specifics if it is to be heard. It is no use declaiming slogans and banging on a drum. Action for change on social and civil issues needs to be both strategic and tactical, with the insight to spot the points on which to stage a confrontation, and also a flair for creating events that grip the public imagination. Unless the public imagination is gripped, nothing will happen. It can be exciting stuff. The disability movement in Lebanon is not short of examples.

The disability movement
Throughout the war there has always been a commitment to holding on to essential human values, a kind of dogged rearguard action by those who have refused to bow to the madness of the political gangsters and the militias. This has been particularly true among disabled people, many of them victims of the violence. The overall aims of the disability movement in Lebanon have been focused on two levels: at the level of disability itself there is the problem of *ad hoc* and inappropriate rehabilitation services — as just one example of a very poor understanding of disability issues in the population generally; at the level of Lebanon there is the problem of how to create a climate where a civic maturity can develop. The two are closely linked. If disabled people had rights under the law, this would indicate both a better general understanding of disability as an issue, and would also imply a civic consciousness on which sound policy could be built.

The history of the movement starts from 1981. Hassan Bsat from Sidon became paralysed in 1979 not as a result of the war, but through a diving accident. His experience of rehabilitation was like so many others: it stopped at the medical response, and after that there was nothing. He stayed in the rehabilitation centre for three years of treatment and rehabilitation:

*It was also a time of coming to terms with my disability — a very difficult period, I cannot say it was not. Every day I lived in the hope*
that tomorrow I would walk. There was some progress in my ability to cope during that time. I learned how to get undressed, wash, go to the bathroom, and so on all on my own. But that is as far as it went. After that, the way seemed to be blocked. I asked myself, is this all? Just rehabilitation exercises, and eating and sleep? Isn't there anything else? I decided I had to get a job.

He managed to get himself trained as an architectural draughtsman, but had great difficulty finding a job afterwards. In 1981, the International Year of Disabled Persons, he joined with others to start various activities with and for disabled people.

> We eventually set up the Lebanese Sitting Handicapped Association at the end of 1981. I was a member of the founding committee. There were six people at the start on this committee, plus sixteen people in Sidon who were members.

Then came the Israeli invasion of Lebanon in the summer of 1982. Two months before, he had finally found work in an architect's office in Beirut, but the invasion put an end to that: it was impossible to reach Beirut from Sidon. So he set up his own home-based business with a machine making plastic signs for hospitals, offices, and other business premises. He began to earn a living from this, and also to work on the activities of the Association.

**The Lebanese Sitting Handicapped Association**

So was born the first organisation run by disabled people in Lebanon. The Lebanese Sitting Handicapped Association (LSHA) now has about 300 members in Beirut, the Beqa'a Valley, and the south. The main trigger for its formation was the enormous increase in the number of disabled people as a result of the war, and the absence of any rehabilitation services which went beyond the medical. Hassan again:

> At that time in 1981 there was no one to speak in the name of disabled people. There was no one who could give advice about integration and the mechanics of it. No one came round the hospitals to give advice to people newly disabled. If there was any attempt at that, it was very individual and random. We saw the need to do something on a general and organised level which would have official recognition.

LSHA started as a response to the needs of people who suddenly found themselves disabled. It also attracted people who had been
disabled since childhood and who had become interested in the issue of rights. They perceived that work with individual disabled people was never going to address the heart of the problem if fundamental rights remained out of sight and ignored. But they also realised that the chances of securing fundamental rights in Lebanon with a civil war going on and the country divided up among militia fiefdoms was very remote. Sylvana Laqis, disabled by polio as a child, is deputy director of LSHA:

The main reason for our existence today is to lobby. But the war has meant that this part of the programme has been asleep, because the government has not been there to ask our rights from. We have asked many things from the State, in particular to establish a special department in the government for disabled people. On this point we worked with other disabled associations, for example Friends of the Handicapped. But the situation was not ready for that. We are hoping to start now that the war is over.

So lobbying is our main aim. But we have found that if we want to strengthen the view of disabled people towards themselves, we have to have some services. We must be realistic. Not everyone who is disabled understands the need for lobbying.

So they have branches in different parts of Lebanon: the south, the Beqa'a, and Beirut. They visit disabled people at home with a team including a physiotherapist. Those who were injured in the war have a particularly hard time adapting to their new situation.

Sometimes we try to contact them as soon as they have been injured before they have left the hospital, and sometimes they refuse to see us then, because they do not want to believe that they are going to be like us. Most people take at least a year to come to terms with, for example, paralysis.

The families of those disabled are profoundly affected too, and Sylvana says that their work is probably more with the families than with the injured people themselves. The families have widely differing attitudes towards the disabled person in their midst:

There was one family whose son, aged 12, was disabled by a shell blast, and his parents put him in a dark room where visitors could not come. They did everything according to their own understanding. We worked with that family for two years before they were convinced of the need to
let him go to a special school. On the other hand there are families who take very good care, and who go to great lengths to get their children to a special school, even though it may be a long way away.

Another example was a young man who had been paralysed and who had been in bed for 15 years at the time we visited him. Fifteen years! Can you imagine? After a year we managed to get him out to a summer camp, and sometimes we take him on home visits to see other disabled people. Now he is much better. He is beginning to study electronics.

All the members of the Lebanese Sitting Handicapped Association are disabled; it has no paid staff and operates entirely with volunteers. This is both a strength and a weakness: it means that everyone is on an equal basis and there is a strong spirit of cooperation and communal endeavour. It also keeps costs low. But against these huge advantages must be set the inevitable inefficiency of an entirely volunteer system, where no one is under the obligations of a contract. Muhammed Halabi, a member of LSHA quoted above, has a degree in computer studies and runs a computing course for disabled people. In his view:

The wheelchair workshop run by the Lebanese Sitting Handicapped Association.
Among the volunteers there is a problem of understanding between those of different educational backgrounds; it is hard to reach a consensus, and you cannot give orders. Working with volunteers is difficult; it is not as efficient as working with paid people whom you can depend on. But paying people would be an enormous problem.

Following the initial impetus of LSHA there are now four organisations working on the social and political aspects of disability in Lebanon: LSHA, the Youth Association of the Blind, the Friends of the Handicapped and the National Association for the Rights of Disabled Persons (NARD).

The Youth Association for the Blind

One of the leading lights behind the formation of the Youth Association for the Blind was Amer Mukaram, already quoted in Chapter 6. His life experience illuminates many of the issues discussed in the first half of this book: the effects of being brought up in an institution; the problems faced by a blind person trying to succeed in a sighted learning environment (the American University of Beirut — AUB); the question of integration versus separation for disabled people; and the need to lobby the government to legislate for fundamental rights.

Amer spent his childhood at a school for blind children with only rare visits home, and was kept almost completely cut off from any meaningful contact with the world beyond the confines of this institution until he went to university. At university he wanted to study Maths, but found that it was almost impossible to record the material at that level either in Braille or on tape, and the lecturers made no concessions for him. He had to abandon Maths and change to Arabic literature and philosophy.

To begin with, other students were not very helpful, and the first person to show him round the campus was another blind student. He found this very disappointing, feeling that if blind people formed themselves into a clique within the student body, they would be even more cut off from the sighted world, as they had been at his school. He was convinced from the start that integration would not be achieved by forming a separate movement of people like himself, and so for the whole of his time at AUB he avoided associating with other disabled people. His thought constantly was how to reach out from the isolated ‘world of the blind’, as he had experienced it through his childhood, to the real world beyond, with
its newspapers, books, cinemas, debates, politics, and relationships:

People say that there is a world of the blind, as though we inhabit a separate world from 'normal' people. But we must dispel this idea. We must have access to the same culture, magazines, etc. There must be a way of doing this.

In 1987, at the end of his student years, he heard about a camp for disabled people and decided to see what went on. He was appalled that all disabilities were lumped together 'in the name of integration'.

The people who ran this camp talked about integration, meaning integration of all disabled people with each other. But where on earth did they get this idea from? Who says that there should be a separate world called 'the world of the disabled'? We are supposed to integrate with society, not with other disabled people only.

After the experience of this camp, he and another blind person decided to run a summer camp for blind and sighted people together. It was at this camp that the idea of the Youth Association of the Blind took root, in 1988. Amer continues:

Let's look at the history of disability politics in Lebanon. Up till 1988 there were welfare associations for the blind which ran blind schools. But there was nobody saying that blind people should be integrated into society. A blind person spends all his or her formative years in one of these schools and then must leave; but they are totally unprepared to go out into society. There is no association which concerns itself with what happens to a blind person after they have left the school. And nor is society prepared to receive them. Society has not been involved in the blind person's development up to that point, and does not see it as its duty to do anything.

That kind of institution creates enormous problems. A specialist blind school is the root cause of the problems. Blind pupils should go to ordinary schools.

It was the need to introduce blind and sighted people to each other which was and remains the main impetus behind the Youth Association of the Blind.

We reject the idea of forming an organisation only for blind people. We must enlist sighted volunteers in our organisation and develop friendships between blind and sighted people so that they understand each other.
YAB is also now working to lobby the government to legislate for integration of blind people in mainstream education: 'The State has the responsibility to create the circumstances through which that can happen.'

Amer is adamant that a separate organisation of blind people is not the way forward if integration is to be achieved:

You hear much these days about the need for disabled people to form their own organisations to demand their rights. We reject this idea. That simply reinforces the idea that there is a dividing line between the two worlds of able-bodied and disabled people. But if we form associations which are mixed between able-bodied and disabled people, this is giving a clear signal that we need to work together on this.

YAB works through such activities as summer camps, a talking magazine, and the involvement of sighted volunteers to widen its circle of contacts and reach more blind people in Lebanon. It also recognises that transport is a huge problem for blind people and it wants to start a project to do something about it. Amer concludes:

There is no State in the world that has the right to say to a person, 'You have no right to enter that building to get educated.' So why should the State say that to disabled people? The law must make it possible for disabled people to enjoy all the rights that other people have. It is society that should insist on this: the government works with their money: they should insist on spending it on these rights. Only the means are different for disabled people.

The Friends of the Handicapped
This perspective, and also the concept of disabled people and able-bodied people working together, are shared by the Friends of the Handicapped, an organisation which was founded in Beirut in 1978, originally concerned with the issue of mentally disabled children. One of the founders was Dr Musa Sharafeddin, who has two children with multiple disabilities, physical and mental. But it has now evolved into an organisation working for the rights of all disabled people. It owes much of its inspiration since the mid-1980s to Nawaf Kabbara.

Nawaf, quoted in Chapter 3, was paralysed in a car accident in 1980 in his early twenties. Already active in student politics before his accident, he went to England to complete his post-graduate studies in 1981, and during the four years that he was there was
exposed to ideas on disability as a social and political issue. In 1984 he returned to Lebanon and started to work with the Lebanese Sitting Handicapped Association. He was then invited to join up with the Friends of the Handicapped to form a branch in the north of the country, working on disability generally.

This marked the beginning of a remarkable series of initiatives and projects by Friends of the Handicapped, working with LSHA and other organisations: in 1985 there was the first demonstration by disabled people against the war in Beirut; in October 1987 the Peace March from Tripoli to Tyre, described very briefly in the opening chapter of this book, which attracted international attention; in 1988 the formation of the National Association for the Rights of Disabled People and, with that organisation, the launch of its Arabic magazine *Asda‘ al Mu‘awwaqeen* (*Echoes of Disabled People*); in 1988 too a major week-long festival in Tripoli run by Friends of the Handicapped.

Friends of the Handicapped (FoH) is an organisation of both able-bodied and disabled people which works on several fronts. Its main aim is to create the climate for integration through lobbying, social action, and raising awareness both locally and nationally. Like LSHA and YAB, it sees the importance of providing services to disabled people, both for their own sake and in order to create awareness among disabled people. It too relies heavily on volunteers, mainly young people, both disabled and non-disabled, who can drive cars, transport disabled children to school and adults to places of work, read to blind people, help children with their lessons, see to the supply and repair of aids and appliances, do home visits, and run group activities. FoH has a core of paid staff, most of whom are disabled.

Seventy per cent of the organisation’s funds come from a variety of foreign donor organisations, the rest from local and government contributions. This funding has enabled them to run an efficient service-delivery system, but the fact that such a large proportion comes from foreign donors creates anxiety about sustainability: they are fully aware of the precarious nature of foreign funding relationships, and are now laying the basis for self-sufficiency through a number of income-generating projects. The most visible is a town taxi operation, The White Taxis, which when started in 1990 was the only telephone-request taxi fleet in Tripoli. (It has since attracted competition from the normal commercial sector.) They have also started a machine-knitting project employing nine disabled people
making jumpers. Their most ambitious project is a proposed shopping complex on land donated by the municipality, the shops to be run by disabled and non-disabled people. It is planned to include a library, a citizens' advice bureau, a hostel for independent living, and sports facilities.

The story of FoH so far has been one of growing confidence and discovery about the reality of social and practical action. They have gained experience about what works and what does not through trying bold and imaginative ideas, some of which have been successful and some not. Among the successes it is worth looking in detail at one particular example of direct social action, less eye-catching than the Peace March, but perhaps just as significant in its way. It involved intensive social action over a sustained period to bring reform to the only institution dealing with disabled people in Tripoli, the Abu Samra Centre.

This place was a kind of total institution where old people, people with both mental and physical disabilities, and those whom their families would no longer look after were incarcerated. Conditions were by all accounts horrendous: there was no heating, no hot water, very little privacy, most of the 'inmates' slept in a vast dormitory, and there was no respect from the staff. When the war broke out in 1975 and international money became available for 'rehabilitation', the management set up a physiotherapy unit. But, according to one former 'inmate', Nasir Halabi,

... they didn't change their attitudes. They kept all the physiotherapy equipment in a cupboard, locked away. The director said to someone who asked why: 'We don't have anyone here who is worth using it on.'

Look, I am a person. I exist. I have my rights. I have as much right to the institution's resources as anyone else. In that place you only got treated if you had some kind of influence with the director.

From 1975 to 1986 Abu Samra was the only rehabilitation institution in north Lebanon. Then in 1986 Friends of the Handicapped arrived on the scene. They thought at first that they could make use of Abu Samra and refer some of their people there for physiotherapy. This led them to understand the conditions in the centre and they tried to create improvements through pressure on the board, but to no avail. After the Peace March in 1987 and the Tripoli Festival in 1988 (both run by disabled people), FoH in Tripoli felt more confident and more determined to do something about the conditions in Abu
Nasir Halabi, former ‘inmate’ of the Abu Samra Institution, at home with his daughter. ‘Look, I am a person. I exist. I have my rights.’

Samra. Some of its ‘inmates’ joined FoH and worked for them ‘on the inside’. Nasir Halabi was one of them:

The director didn’t like this and tried to get rid of what he called the trouble-makers. He started by cutting off the water and then said we had to be in bed by 7 pm. It was very insulting to treat us like that.

This crisis provoked a confrontation with FoH. They gave the director an ultimatum:

Either we sort this out through negotiation or through direct confrontation. If it comes to confrontation, society will be your judge.

Negotiation did not work; the director did not listen. He threw the ‘trouble-makers’ like Nasir out of the institution. FoH immediately contacted other groups in the town, women’s groups, youth groups, and people in key positions, and told them what had happened. Nawaf Kabbara takes up the story:

We used a number of tactics. One was to get a friend who was a journalist to go in with a video camera, not for real, but just to scare the director and show that this was a serious business. The same with another journalist who did an interview with him. All this was to put pressure on him. He got more and more anxious.
At the end of the fasting month of Ramadhan there is a special festival where traditionally people give presents. FoH picked this day as an appropriate moment for their next move. Members of FoH turned up at six in the morning to take people from the institution to the mosque for prayer, but were denied entry by the director. They again alerted groups and individuals in the town to what had happened, then they announced their intention of visiting Abu Samra in the afternoon to spend a few hours with the 'inmates'. The director panicked and asked the Syrian forces to intervene. But the president of the board got wind of what was happening, and, to avoid embarrassment, sent someone to open the door and let them in for the afternoon visit. Nawaf remembers:

*But the whole thing created a huge furore in the city and raised a campaign against the director. This created a lot of pressure on him, and he eventually resigned.*

*These were the tactics we used. The important thing was that it showed that people in the city, and in particular the disabled people, were not prepared to tolerate that kind of institution any more. That's why it was a turning point as far as disability was concerned.*

Nawaf Kabbara in his office at Friends of the Handicapped.
What happened in Abu Samra? First they changed the director and the president of the board. Then they partitioned the large dormitories, removed all the petty regulations, and improved the food. Next they recruited professional social workers to work with them. Today Abu Samra is still an institution, but it is no longer inhuman.

This story shows some impressive skills in social action. There are two key points: first, FoH had a sense of timing, of how to provoke a confrontation and of when to go for the show-down. Second, strong alliances with other groups and key individuals in the community provided the crucial pressure to force the director out; having able-bodied members and volunteers undoubtedly made these alliances easier, since FoH were not perceived as an exclusive group consisting only of disabled people, but as an open organisation of people with a commitment to bringing about change.

This example created a positive reform in one institution and also demonstrated that disabled people and their friends could change things if they went about it in the right way. Other examples of social action initiated by FoH have shown a similar sense of visible theatre and timing, and of picking the ground that people beyond the disability movement can relate and respond to. The Peace March in 1987 was the most notable.

The Peace March had three aims: first, to show an overwhelming will for peace and unity; second, to create a network of civilians all over the country that could organise and lead further civil protest activities; third, to end the marginalisation of the disabled community and ensure its place in the new civil Lebanon.

The march took months to prepare, and had to overcome a great deal of scepticism in Lebanon itself. The critics accused the organisers of, among other things, 'using disability for political purposes', as though disabled people are somehow outside and immune from the political process. Contacts were developed with organisations outside Lebanon, and arrangements made to film the whole thing. It was routed to pass through the main crossing points between the fracture zones on Lebanon's mosaic map. Fifty-six people in wheelchairs started from Tripoli in the north, joined by more than a hundred walking disabled and able-bodied people who acted as pushers and co-marchers. Those who took part were from all confessions in Lebanon. At each militia checkpoint there was a point of tension as hardened militiamen wondered how to react. In the major towns, rallies with music and dancing were held. By the time they reached Tyre in the south, the publicity they got en route,
both nationally and internationally, ensured a huge crowd and an impressive welcome from the local dignitaries and politicians.

The march was a leap of courage, faith, and imagination at a very dark moment; there were not many signs of hope at that time in Lebanon. It did not stop the war, which went on for another three years, nor did it spark a groundswell of civil protest as intended. But it restored faith both inside and outside the country that people were prepared to put themselves on the line for deep and basic principles, in a country were many had lost hope of sanity ever returning. And, perhaps almost by the way, it put disability as an issue firmly on the map in Lebanon.

It was important to keep the momentum going. In 1988 FoH drew up a list of principles, in addition to the original aims of the march, which it felt the march had demonstrated and which needed to be kept in view with further planned events:

- to reactivate civil defiance to the state of violence and military control over the country;
- to encourage young people in particular to express their concerns through non-violent civil action as a platform for new ideas, commitment, and potential;
- to encourage different interest groups to work together for the common interest of peace and a civil society;
- to show that disabled people could play a significant role in creating the will and climate for a non-violent civil society.

With these goals in mind, almost a year later in August 1988 FoH launched a Festival of Peace in Tripoli. The somewhat unlikely venue of a disused railway station set in a large open space, long since taken over by nature, was turned, for a week, into a sort of medieval market fest where stalls were set up by glass blowers, potters, sweetmeat makers, and traders in various other handicrafts. The emphasis was on Lebanese culture and the need to treasure it when everything seemed to be falling apart. A cafe was set up with water pipes and traditional coffee-making. Story telling is an old tradition in Lebanon; a story teller (hakawati) was on hand to recount the exploits of heroic figures like Antar, Leila, and Abu Zeid al-Hilali. Plays and music were performed, and in one corner was an ancient sandouq al ferje, the Middle Eastern equivalent of a kind of magic lantern, where a story is told by a story teller who rolls illustrations across a drum set on a special stand.

More than 6,000 people attended the Festival of Peace. For the
first time in Tripoli in five years there was something which drew people out of their homes after dark; in the transformed environment of an old railway station, a sense of life and of the heritage of this ancient land had returned. Not an insignificant contribution to the rebuilding of a civil society.

The National Association for the Rights of Disabled People
The fourth organisation of disabled people in Lebanon is NARD, the National Association for the Rights of Disabled People. This was founded in 1988 by four people active in FoH and LHSA, to coordinate and focus efforts on lobbying and advocacy among the other organisations. It also intended originally to establish a research centre on disability in Lebanon and the Arab world generally. Its main achievement to date has been the production of a high-quality quarterly magazine, Asda’ al Mu’awwaqeen (Echoes of Disabled People), which is distributed throughout the Middle East.

In the light of the arguments in Chapter 6 over the role of the State and the role of private voluntary action, Lebanon represents a society where the collapse of the State has indeed been replaced by private initiative, but the balance has swung too far in that direction. Without a legal framework and recognition of rights which provide a baseline for mutual understanding and discussion, it is not possible to raise issues as matters of principle. The creation of a civil society can only succeed if the general intent towards the common good is enshrined in a civil code; it cannot be left entirely to individual good will and initiative.

The disability movement in Lebanon provides a microcosm of this perhaps obvious fact. The main thrust of the movement now is to get disability legislation on to the statute books. But now that the war is over, disability ranks low in the priorities of politicians. The only way the movement is going to succeed is to continue to raise awareness among the general public by imaginative and creative events like those described, coupled with systematic and dogged efforts in approaches to politicians.

The way of social action in Lebanon is already impressive: it has not ghettoised disability, but has enabled disabled and able-bodied people to work together on a common project, the most important project of all, which is the re-establishment of mutual trust and cohesion after seventeen years of war.