

PART TWO

The issues



Huda, a member of the Baqaa community centre for disabled Palestinian children, Jordan.

The experience of disability

'Social change initially comes from us, from disabled people. It has to.'
(Rachel Hurst)

Disability: who accepts?

Disability is perceived, by able-bodied people, as a tragedy, a loss, or a deficiency; these powerful negatives elicit either fear, pity, or admiration, depending on how the disabled person 'copes'. But is that the way disabled people see it? When we speak of 'acceptance' of an impairment, what do we mean? Who has to accept it — the disabled person, or everyone else?

What we have to examine is why negative attitudes are held, and how they can be changed. The negative response of most able-bodied people to disabled people is based mainly on ignorance: they assume that disablement is a catastrophe, and they fear it; fear creates awkwardness, avoidance, and prejudice. But a first step in changing perceptions and attitudes is to understand the experience of disability for those who are disabled. We will look at the question of prejudice and discrimination later in this chapter ('Attitudes: breaking out of the vicious circle'), and in Chapter 4 ('The politics of disability'). Here we will explore the way in which the impairment¹ itself is viewed by a number of disabled individuals.

Is it possible to accept an impairment? Many disabled people would say they can never 'accept' it, in the sense required by an able-bodied and non-understanding world. They resent being told that they have to 'come to terms' with their condition; rather it is the able-bodied world that has to accept or come to terms with disability. What disabled people have to 'cope with' is not their impairment, but the hostility, prejudice, and discrimination that they

meet every day of their lives — for no other reason than that they are disabled.

This is true. But it is also true that there is a process of adjustment by the disabled person which is essential if life is to have any meaning for him or her. The road to adjustment for the disabled person is a lifelong process of self-discovery, the discovery of a new identity, with all the ups and downs that self-discovery for anyone entails. But adjustment requires an understanding of that identity, not only by the disabled person but by those who relate to her or him. Negative attitudes, prejudice, and discrimination make it impossible or very difficult for this adjustment to take place. At what point can the circle be broken?

It is at the beginning a question of identity. We have already seen in the interview with Venkatesh that for him blindness is not a loss, but an opportunity for deeper development as a person:

What gives worth to this life? It's not what you have or what you don't have. It's the ability to enjoy what you have, no matter what. If you don't have that grace, you can't enjoy anything, whether you have sight or not, or even if you're a millionaire. That fundamental realisation has been crucial to me. Because being disabled is nothing wrong; there is no value on it. If anything, the human value of being yourself can increase immensely, because of the sensitivity to yourself that can develop. I mean, pain is part of growth. I think trauma is also a source of motivation. You can channel the trauma.

Rachel Hurst, of *Disability Awareness in Action*, is a wheelchair user as a result of a form of congenital muscular dystrophy; the condition was not diagnosed until many years after the symptoms had appeared, and for her the diagnosis was a breakthrough to her real identity:

I was actually born with a disability. But it was not diagnosed for a long time, until I was 39 in fact. But once it was diagnosed, it was like recognising myself at last. It was a total liberation. It sounds crazy, and obviously there are times when I wish I could walk, but I now feel much more secure in myself, now I know what I myself 'am'.

Actually when they diagnosed it and told me that I must have had it since I was born, I did not believe them at first; but then I realised it was true and it altered the whole way I had perceived myself ... I mean I had always perceived myself as aggressively able-bodied, which meant that for years I had been trying to do things I couldn't actually



Rachel Hurst, of Disability Awareness in Action: 'Social change initially comes from us, from disabled people. It has to.'

do. I feel very much more comfortable with the me that I know now than with the one I was trying to be. There was an uncanny feeling that that wasn't the real me.

Moses Masamene is a blind lawyer from Lesotho who, like Venky, lost his sight gradually in his late teens through *retinitis pigmentosa*. Now in his thirties, he sees his blindness as part of his personal identity, in the same way that maleness is:

I take it to be another endowment, in the sense that if you are a male or a female, it is what you are. I take my blindness to be an identity; it is a human attribute, which should not prevent anybody from achieving his aspirations. So it is a question of counteracting social barriers which oppose unsightedness.

Both gender and disability are 'constructed', in the sense that on top of the biological facts of sex and an impairment such as lack of sight there are social expectations which determine the options for those concerned. But Moses recognises that adjusting to this new identity is not necessarily easy. For those who were born disabled, the question of identity is obviously easier than for those who become disabled later in life.

There is early disability and late disability. With early disability there is no problem, because you grow up with it. But with late disability

there is bound to be some emotional instability as you try to get over that. But with time, through contact with other blind people, and counselling from your peers, you do get over that.

Be aware that in life anything can happen, because disability is like the air that we breathe: it doesn't give you any notice. When it happens, it is important that one should cry over the loss and then accept it and accept a new identity.

Of course, becoming disabled does involve a loss, and the disabled person may go through all the agonies of denial, anger, and rejection before reaching the stage of adjustment which amounts to acceptance. Some may remain stuck at anger and rejection and never reach the stage of acceptance at all, living out an existence of bitterness and regret because they cannot accept the stigma. On the other hand, a recently disabled person may not experience any difficulty in adjustment at all, and may slip straight into the new identity. Whatever the case, the experience of millions of disabled people all over the world demonstrates that 'acceptance' in the sense of believing in the new identity is the necessary prelude to leading a fulfilled life with the new reality.

Acceptance or resignation?

But what does acceptance mean? Is it just a question of getting used to a loss, a kind of resignation in the face of unalterable odds? If acceptance means nothing more than resignation, then little of positive value can happen. Resignation is tantamount to fatalism. Acceptance is more: it involves a positive adjustment to the new identity, in which self-image and self-esteem are not impaired, but remain very much intact; they may even be enhanced, as in Venkatesh's case.

There are no simple prescriptions for how to attain acceptance, but it is a process which certainly involves all the non-disabled people, especially the family, who relate to the disabled person. Pity, neglect, or over-protection by them obviously make it very much harder. This is especially the case when a child becomes disabled; the whole family will be faced with the problem of how to react to and accept the new situation, and it may well be harder for the family than for the child.

Alexander Phiri lost both legs at the age of ten when he was hit by a car. He came from a very poor family in a village in Zimbabwe, and once his parents realised he had lost his legs, they abandoned

him in hospital as no longer of any use to the family; he had become a major economic burden. The hospital placed him in an institution from where he was able, against considerable odds, to get educated, and eventually graduated from college into a good job as a designer.

Once established, he decided to trace his family, and after much enquiry tracked them down in a different village, driving up to their hut in his own car. His brothers and sisters had been told that he was dead, and his mother had the greatest difficulty in dealing with the astounding situation of his sudden reappearance after a gap of 15 years. (His father had meanwhile died.)

Alex is now the main provider for his extended family. He holds no bitterness for the childhood rejection:

They thought I was hopeless. But in fact I am the only educated member of my family, thanks to my disability. So it was like a blessing in disguise that I became disabled. Otherwise I would not have got to where I am today.

He has become a leading and highly articulate member of the disability movement, not only in Zimbabwe but also in the southern Africa region. The irony is that rejection by his parents led to his present position as the family's main breadwinner.

Rejection of a disabled child as an economic burden certainly happens, especially in extremely poor communities. Other dramatic stories similar to that of Alex were told by several people interviewed for this book. They were the lucky ones: others rejected do not survive. But perhaps more common than rejection is over-protection by the parents, fearing that their child will not be able to cope and must therefore be treated as an everlasting baby.

Samir Ghosh from Jemshedpur in northern India had both arms amputated at the shoulder after being electrocuted at the age of eight. His parents, unable to accept this catastrophe themselves and sure that he would not be able to deal with it, told him that his arms had been taken away 'to be washed', and that they would soon be brought back. As the days went by and no arms appeared, he asked the surgeon when his arms would come back:

'When are you going to bring my arms and hands back to me?' But he had no answer. He just took a chair and sat with his face in his hands. Then he realised that my parents had been telling me all these things. But he didn't blame them. He realised they just didn't know how to react. I was in hospital for three months. But the doctors felt I was

fairly strong to take things. So the doctor said, 'I don't think your arms are going to come back, but we will try to help you get some new "hands".'

It was Samir who surprised his parents. He did indeed acquire new 'hands': within weeks he was writing with his foot, and announced he was going to return to school; his parents objected, thinking that he would be an embarrassment (presumably to them, if not to himself), but he insisted. Fortunately the headmaster was enlightened: he welcomed him back at a school assembly when he announced, without great drama, that Samir had had an accident and 'might need a little help from time to time'.

Samir, positive and outgoing, was accepted by his peers as a full member of the school. His classmates helped him with homework at first, but he was soon able to write as quickly as them with his foot. He completed his studies in India, and eventually gained a doctorate at the London School of Economics. He now holds a senior post as management consultant in one of the largest firms in India. He is more or less independent; the only aid he uses is a dressing hook which he holds in his mouth to pull up trousers and socks. He eats, writes, uses the telephone, and drives a car entirely with his feet. This acquisition of independence has been gradual, and he is still, in his late thirties, discovering an increasing range of techniques for doing things differently.

This story is not included here to portray heroism, but to make the point that positive acceptance of such an apparently appalling loss is possible. An impairment need not be an obstacle to a deeply fulfilling life. Samir was accepted by the school because he refused to see his impairment as a bar to a normal life, despite his parents' attitude, and that has been his story ever since. Without a positive attitude from him, none of this would have happened. If he had sat at home 'demanding his rights', no change would have occurred.

But inward, positive acceptance of impairment is a journey which not only the disabled person has to make. We have seen in the case of Alex Phiri and Samir Ghosh that parents may have difficulty in coping with a disabling accident to their children. Likewise for a mother to give birth to a disabled child can be a traumatic experience: with all the social and cultural prejudice against disability, coupled with the feelings of failure and guilt in herself, what should have been a joyful event turns into an apparent tragedy. The arrival of a child who may be eternally dependent

seems like a blow of extra cruelty by fate. The father will almost certainly have similar feelings, deepened perhaps by the sense that somehow his manliness and family honour have been besmirched.

Some people in the disability movement say that they look forward to the day when a mother who gives birth to a disabled child will rejoice as deeply as if the child was not disabled;² that would be the real indication that disability is no longer feared or abhorred. We are into difficult territory here. If disability is not a negative, should it be prevented? If it should be prevented, what does that say to people living now who were born disabled? Should they have been 'prevented'? For now we will simply note this deep dilemma and return to it in Chapter 4, 'The politics of disability'.

Whatever the ethics, there is a certain reality that must be faced. The reality in many cultures is dismay when a disabled child is born. **M. Mathias** is the Secretary of the Karnataka Parents' Association for Mentally Retarded Citizens, based in Bangalore, south India. His daughter Tanya, now grown up, was diagnosed as having a mental disability at the age of four months.

The doctor told us: 'You have a mentally retarded child and she will be the ruination of your family.'

At this time, in the early 1970s, there was very little awareness in India, even among educated urban people like him, about mental illness and mental disability; the two were lumped together, and there was a general fear that 'madness' was a hereditary disease which must be kept out of the family at all costs. His brother had warned him not to marry into a family 'where there was madness'. How did he and his wife react to the arrival of a little girl diagnosed as 'mentally retarded'?

I felt I had let my family down on three counts: to start with, my first child was a girl; second, I had brought 'mental illness' into the family; and third, the doctor had said she would be the ruination of my family.

What was my reaction at that point? The normal human response: shock, guilt, denial. I think it took me about 20 years to accept my daughter's disability. My wife reacted the same way. But she is over-protective to some extent, which is another form of escape. I think I personally have finally accepted her, although I have had a few knocks when it has been clear that I have been kidding myself. I have adapted to the situation. But I have suffered the loss at each stage of what she would have been had she not been disabled.

The family also has to face relatives and friends; they too have to find a way of dealing with the situation.

Our relatives and friends reacted with a studied indifference. They didn't know how to respond, so they pretended the problem didn't exist, like us. It was the first time in our whole family that such a thing had happened.

Eventually, when Tanya was in her teens, Mathias and his wife were instrumental in setting up the Karnataka Parents' Association for Mentally Retarded Citizens. This organisation provides support and counselling to parents, lobbies for changes in laws governing disability, and runs training courses for teachers in special education. Out of their own trauma has grown something positive and life-changing for many people.

It is important to point out here that the sex of their child was considered a matter for regret: the double rejection of girls and women who are disabled is a huge topic that has received very little attention in the literature on disability. As mentioned in Chapter 1, neither the women's movement nor the disability movement has previously addressed this issue adequately. 'To be male in our society is to be strong, assertive and independent; to be female is to be weak, passive and dependent, the latter conforming to the social stereotypes of the disabled. For both categories the disabled woman inherits ascriptions of passivity and weakness.'³ Indeed, one feminist academic asks: 'Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive and needy.'⁴ At this point we can only note this enormous gap in understanding. It will recur in the country case studies, especially on Zanzibar and India.

Support and counselling for the parents of a disabled child are extremely important. It is no use pretending the problem does not exist, nor is it at all helpful if everybody, including the medical professionals, treats the whole matter as an unmitigated tragedy which will be 'the ruination of the family'. Doctors, midwives and other health workers need training in how to counsel parents and to give them support in the vital early stages. In particular, realism is essential. A common reaction is for parents to refuse to believe that their child has a permanent impairment and spend many fruitless years and money they can ill afford on trying to find a 'cure'. Good medical care at the beginning can certainly reduce the effects of the impairment, but the medical profession in general, especially in



Patricia Mazambani and Anita attend a mothers' support session at a township in Harare. 'When I am together with other mothers, I feel free. We feed each other with ideas.'

developing countries, is hooked on the 'cure or care' model which encourages the fruitless search; we will return to this subject in Chapter 5.

Acceptance of disability is a complex and life-long process involving many people and many factors. To regard permanent impairment, either in a newborn baby or in an adult, as a loss, is an understandable reaction; but if it is allowed to persist, such a reaction is not likely to lead to any constructive life process, either for the disabled person or for the non-disabled people around him or her. It is a new circumstance, which everybody has to adjust to — and come to terms with.

But let us be very clear and very careful about what is being said here: permanent impairment may or may not be a personal tragedy for the person concerned, but whatever it is, there is no reason for society to turn it into a handicap. Acceptance of an impairment does not mean accepting the role placed on disabled people by an able-bodied society. The social expectation of disabled people is that they will shut up, sit at home, and not complain. Acceptance of the impairment is one thing; but acceptance of such a passive, unconstructive, and disempowered role imposed by society is of

course quite out of the question. What we have examined in this section is how some disabled people relate to their impairment. Of far greater importance is how the rest of the world relates to them.

Attitudes: breaking out of the vicious circle

It is attitudes that disable. If able-bodied people did not react with horror, fear, anxiety, distaste, hostility, or patronising behaviour towards disabled people, then there would not be a problem. Discrimination and prejudice create the sense of being disabled that leads to further discrimination and prejudice. How can this vicious circle be broken?

The testimonies from the disabled people interviewed for this book emphasise again and again that the process of attitude change starts with disabled people: their attitude towards themselves and their own disability. This perhaps sounds the wrong way round: surely it is able-bodied people who have to alter their attitudes first? But as with people suffering oppression of any kind, the truth is that the oppressor is not likely to change behaviour unless the oppressed person makes the first move. The harsh reality is that if disabled people see themselves as victims, they will be treated as victims; if they are sunk in self-pity, they will be perceived as pathetic; if they are hostile towards non-disabled people, they will be shunned; but if they refuse to see themselves as victims, if they claim their own dignity, see themselves as positive and able to contribute, they will be seen as positive and able to contribute. This is not at all the same as saying that disabled people should be quiet, stop complaining, and settle for some kind of half-life. Absolutely not. The issue for disabled people is ultimately one of self-esteem, of refusing to accept the role of victim. There are many different ways of expressing that dignity, but it lies at the heart of whatever choice disabled activists make, whether strongly militant or quietly persistent. In the words of Rachel Hurst of Disabled People's International: 'Social change initially comes from us, from disabled people. It has to.'

Samir Ghosh from Jemshedpur subscribes very strongly to the idea that disabled people will be treated according to their own attitudes towards themselves. In his opinion, much of the awkwardness displayed by able-bodied people is more the result of ignorance, fear, and lack of familiarity than outright prejudice. Because disabled people in India tend either to be in institutions or confined at home or are beggars, able-bodied people have few opportunities to meet them or form strong relations with them.

Samir therefore makes a point of putting people at their ease and has no hesitation in talking about his impairment if that helps the process. He feels that every person he meets is probably curious about how he manages with no arms, and is basically anxious to be able to relate to him normally.

Furthermore, says Samir, disabled people should not be deterred by one or two negative experiences:

I take the attitude that people are nice, people are good. But I think human beings tend to bank on their bad experiences, rather than their good experiences. We tend to judge the whole human race on just one or two bad experiences. For example, I once went into an office to ask for an address, and they told me to get out because they thought I was a beggar. That used to disturb me, but it doesn't mean that I am not going to go to any other office to ask the way.

But it is very hard. Every time a disabled person goes out into the street, he or she has in a sense to start from scratch: the looks, the avoidance, the awkwardness, the prejudice are all there, every time. Dealing with these things positively time after time gets very wearing. Disabled people are, after all, only human; they may be forgiven for getting impatient with other people for not recognising that simple fact.

The dynamics of prejudice

For many disabled people, rejection is catastrophic: it provokes despair and retreat, which in turn widen the gap and produce further rejection and stereotyping. They become literally disabled by the social attitudes they meet every day of their lives. They end up with a profoundly damaged psyche that is also a feature of other oppressed people: children molested or beaten by their parents, women living in fear of violence, or whole peoples subjected to institutionalised discrimination down the generations.

How can human behaviour be changed? How can this most vicious of vicious circles be broken? There are basically two views on this. One view insists that human nature is fundamentally flawed, and human beings must be prevented from transgressing through coercion and legislation: make it illegal to discriminate against disabled people, and prosecute when it happens. The other view contends that human beings can be influenced, enlightened, and persuaded, and that prejudices and fears can be altered only by the people who are the targets; change has to start by disabled

people taking the initiative, by refusing to see themselves as victims, and by being outgoing in their relations with able-bodied people. Both views were expressed by people interviewed for this book, with the second by far the more dominant.

The truth, I think, lies on both sides. People can be influenced, but legislation is vital. Laws need not be viewed as an instrument of oppression; they are an essential expression of the values of a civilised society. A society without laws is indeed lawless. That is why getting disability legislation on to the statute book is a major objective of most disabled people's advocacy groups in the world today.

The validity of both views needs to be recognised by the other. Certainly we need laws, but they will not have any effect if attitudes do not change; we cannot ignore the need for influencing people through example and modifying our own attitudes. On the other hand, if our view of human nature is that it can be changed only through legislation, then that rules out the whole enterprise of development, not to mention education.

Let us stay with the view that people can be influenced. It is not an easy matter at all. On the one hand, changes in attitude must begin with the disabled person's own self-esteem: unless that is positive, nothing can happen. It is very difficult to form a constructive relationship with someone who is bitter and hostile to the world, or lost in self-pity, or angry that they are still alive. On the other hand, self-esteem cannot be raised in isolation from the social environment: we are all, whether disabled or able-bodied, a mixture of many influences, hereditary, environmental, and social, and our own attitude towards ourselves is not usually, except in rare cases, something which we as individuals have complete control over. If the social environment is oppressive and casts us in the role of victim, then inevitably that is the way we tend to see ourselves; it is very difficult to break out of this strangle-hold.

The question then becomes: if the answer lies inside the disabled person, what are the mechanisms by which an inner source of strength can be discovered? How do you start building self-esteem in an environment which continually undermines it?

Both disabled and able-bodied people need to be sensitive to the dynamics of prejudice, and they must work together to deal with them. There has to be acceptance of the disability by the disabled person, and a realisation that the process starts with a positive self-image. Able-bodied people need to make an extra effort to understand the difficulty of this process and avoid pandering to self-

pity or indulging in over-protection. Robust friendships are needed, not kid gloves.

I am convinced by the testimonies of many people that attitudes can be changed, even in the most unpromising circumstances and under the weight of apparently insuperable cultural discrimination. The many examples quoted in this book illustrate how the circle may be broken. It is significant that all the disabled activists I interviewed insist that their work is primarily with disabled people, in enabling them to understand the causes of their oppression, to feel good about themselves, to walk tall. From that position change can start.

Heroes, heroines, and haloes

There is another aspect of negative attitudes that is possibly more insidious than outright rejection, because it appears to be benign. It is the phenomenon of hero-worship. Some people surround disability with a kind of halo which designates the disabled person as a hero or a saint. But both rejection and hero-worship are equally disabling.

Nawaf Kabbara from Lebanon was paralysed in a car accident in his twenties. Before his accident, he had what he describes as the 'normal' attitudes towards disabled people: pity for their condition and admiration for them if they coped well. For him disabled people were in two classes: beggars or heroes. But after his accident his ideas changed. He did not see himself as a hero:

Why is it wrong to regard disabled people as heroes? Because we are not heroes. It just happens that things have changed in the way we do things; we are doing them in a different way. Of course there are challenges. You have to 'cope'. Some do that better than others. But it is not heroism. It is just a life you have to carry out.

Regarding disabled people as heroes or heroines is another form of labelling. Labels disable because they do not present the person for what he or she really is. Being regarded as a hero is ultimately very discouraging if you know perfectly well that you are not; it implies a shallowness, artificiality, and lack of seriousness in the relationship which is profoundly unsatisfying for the disabled person. It also inevitably entails failure when he or she does not live up to the expectations that hero-worship imposes.

While non-disabled people must be aware of the dangers of hero-worship in relating to disabled people, disabled people themselves

also have to be sensitive to the risk of playing the hero, especially if the trauma of disability fires them to succeed and 'beat the able-bodied at their own game'. Building self-esteem can go over the top. Venkatesh recognised this danger in himself:

There's a kind of determination to beat people at their own game. But one should not get lost in it. I got lost in it, and came out of it. Because you can overdo it, and therefore lose touch with yourself in trying to be that superman. The trip becomes getting a better job, earning more money, having status. These are the social parameters of someone who is doing well in life. So I was caught in that, and I had to get out of it. I've passed a stage where I don't have to do that because I can be just myself now. But it took a long time.

Such an awareness is not reached quickly. We all, whether disabled or not, spend our lives on a journey of discovery about ourselves in relation to our own character and the way it reacts to events. Disabled people have an added dimension to their journey, which is the identity created by their impairment, and they are, like everyone else, continually going through shifts in perception about themselves. The process of attitude change is life-long. And for everybody, whether disabled or not, the way people relate to us is determined by many factors, but most of all by the way we feel about ourselves.

The point about attitudes, finally, is that disabled people just want to be themselves and accepted for what they are. They are people with different abilities, like anyone else, with their own desires, ambitions, weaknesses, prejudices, perceptions, emotions, and hopes, like anyone else. In the final analysis we all have impairments: those who are referred to as disabled just happen to have more obvious impairments than others.

Role-models: breaking with stereotypes and stigmas

Some of those already quoted in this book are examples of 'successful' disabled people. Samir Ghosh has a PhD from the London School of Economics and is a much sought-after management consultant in India. Venkatesh was 'making it' in the corporate sector in Bombay before he decided to work full-time in the disability field. It is not my intention to extol the virtues of such success, which (as Venkatesh says) can be a trap and lead one into missing the point about life altogether. And it is no help to a disabled woman in a remote Indian village to be told that she too

could get to be President if she tried hard enough. Such lack of realism is certainly not the point. But it is important to examine role-models, because negative attitudes by non-disabled people and low self-esteem by disabled people have much to do with what disabled people are perceived as being able to do and not do. The process of breaking out of the role of victim involves looking hard at role-models.

It comes back to self-perception and self-esteem. Do disabled people perceive themselves as able to argue for their rights, join unions, and hold down serious jobs? Where disabled people do these things, they provide positive, confident role-models for others. Where these things do not happen, alternative role-models are not on offer and the negative syndrome of the 'helpless victim' is perpetuated. The problem, once again, is how to create the alternative role-models and break the cycle.

Rungta is the president of the National Federation of the Blind in India, and a practising barrister. He recounts an incident in a hotel restaurant in Delhi where the staff cast him in the role of a helpless blind person and treated him accordingly:

A few months ago I decided to go to the Hotel Meridian for a meal, with my car and driver. We got out of the car and went into the restaurant. I placed the order with the waiter. That waiter and the lobby manager called my driver and told him that such and such a dish costs 70 rupees, another dish 80 rupees, and so on: would this man be able to pay? When my driver came and told me, I went to the lobby manager and asked, 'What were you saying to my driver?' And for two minutes I spoke in English and he kept mum. He did not even expect me to speak English. Then he said, 'Sorry, sir.' I said, 'What do you mean, sorry sir? You can't say this kind of thing to the customer. If the customer doesn't pay, then you have a case. But you have no business to say such things before the bill is paid or not paid.'

That represents the attitude and the feeling. That lobby manager did not expect me to patronise that hotel. He did not imagine that I could own a car or speak English. These attitudes are not due to economic factors; they are due to prejudice about blindness.

No doubt the incident was an educational one for the lobby manager. Rungta makes a point of being assertive in such situations: he refuses to let the matter pass without comment, and declares his disgust with vigour. It is a way of breaking out of the vicious circle, although to do it day after day must indeed be wearing.

We are talking about the need for major shifts in perception in both able-bodied and disabled people. What are the forces that can produce these shifts? **Muhammed Osman** is a founder member of the Nyala Association of the Disabled in the Sudan. He has a condition called spinal muscular atrophy, which means that his muscles are growing progressively weaker, and he now uses a wheelchair. The event which triggered a change of attitude in him was when he finally heard the truth about his condition:

At the beginning it was so hard to live with such a reality, to realise that you would never be like the others. But in 1980 I went to Egypt and there I met a doctor who told me certain facts: it was a genetic disease, and it was incurable.

This was a turning point for me, because I realised that if I couldn't get a cure, I should do something that will help other disabled people. It was a real turning point, because I realised that I should no longer waste any time in pursuing medical treatment. I should instead take a social approach to it. Realising this, I began to think about doing something. Well, it turned out to be bringing disabled people together to discuss these problems.

Once it was clear to him that he was disabled rather than 'sick', Muhammed was able to relinquish the role of 'patient' and become



Muhammed Osman, founder of the Nyala Association of the Disabled: 'I realised that if I couldn't get a cure, I should do something that would help other disabled people. ... It turned out to be bringing them together.'

active: he brought disabled people together in his home town of Nyala, which led to the founding of an association of disabled people. (We will see more of this example in Chapter 4.)

The question of role-models is also linked to that of stigma. For many people who become disabled as adults, it may be very difficult to accept that they are now part of a population referred to as 'disabled'. This is particularly true of ex-combatants and war veterans, who by the nature of things have lived aggressively able-bodied lives, may have always identified with 'macho' behaviour, and cannot accept that they are now, as they see it, incapacitated and classed with people they may have formerly despised. This may be one reason why, in a country like Zimbabwe, it is rare to find ex-combatants in the disability movement.

At the age of 18, **Mike du Toit**, a white South African, became hemiplegic (one side of his body was paralysed) after a car accident. But even though he trained as a social worker and clearly has a well-developed consciousness for social justice, he was determined not to identify himself with 'the disabled' after his accident, perhaps subconsciously influenced by the tough, rugby-playing ethos of his society, and therefore not willing to join a group he instinctively saw as carrying a stigma. But as a social worker, he attended a Rehabilitation International (RI) congress on disability in Winnipeg in 1981. RI is an organisation consisting primarily of able-bodied professionals dealing with disability; out of 3,000 delegates at the congress, only about 200 were disabled. These few disabled people demanded 50 per cent representation on the board of RI, but this request was refused. The refusal was a watershed in the whole politics of disability: in a dramatic moment of self-discovery and self-assertion, the disabled people responded by leaving the hall, meeting in another room, and setting up their own alternative organisation, Disabled People's International (DPI), run entirely by disabled people.

For Mike, this moment was a turning point in his self-perception: he suddenly understood that it was not only credible but important to be identified with this group; having gone to the congress as a 'social worker', he returned as a 'disabled person', and he has been active in the disability movement ever since:

I think until then disability for me was very definitely a personal thing, and it was a tragedy; it was something you felt sad about; it wasn't in any kind of way something that was exciting. Winnipeg for me changed all that. There were all these professional carers giving

their papers about what they were doing to help disabled people. And there were disabled people confronting them head-on, asking pertinent questions and exposing the complete inadequacy of services for disabled people. On a daily basis they produced a newsletter during the conference that satirised the speakers from the previous day. It was exciting and positive.

The point is that both non-disabled and disabled people are part of the business of stigma-attachment and stereotyping. For disabled people, breaking the stereotype means being proud of their identity and creating role-models that do not perpetuate the syndrome of the 'helpless victim'. For Mike du Toit, excitement at the power revealed by disabled people when they were speaking for themselves in their own interests was enough to trigger a major shift of perception in him. The role models available in Winnipeg showed him another way: he had finally overcome the stigma and accepted his impairment as a positive identity.

The politics of disability: what is at stake?

*'Disabled people have not benefited from charity,
because charity is not part of the development process.'*
(Joshua Malinga)

An individual or a social issue?

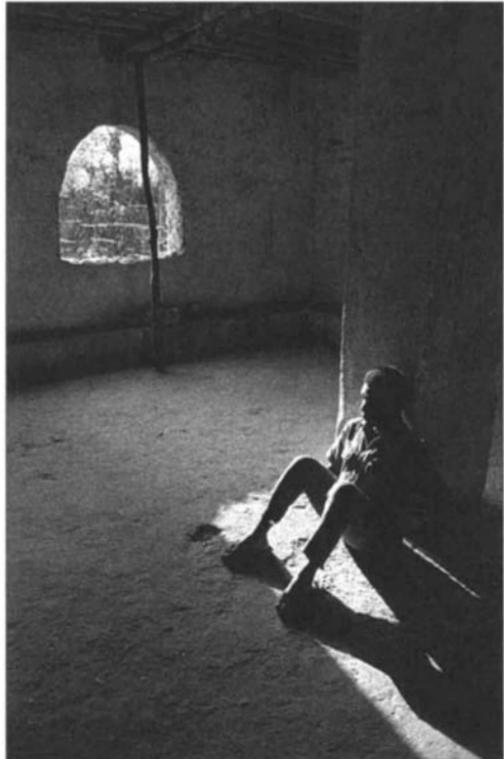
Politics is about power and control. Ultimately, whether we engage in active politics or not, the central political issue is how much control we have over our own lives and the decisions that are important to us in shaping our lives.

Throughout the world, regardless of culture, disabled people have generally been seen as incapable of taking control of their own lives. There are three broad attitudes towards them among able-bodied people: they may be regarded as lesser beings to be rejected; or they are seen as objects of charity; or they may be viewed with 'benevolent neutrality', which is another way of saying: 'I don't wish to become involved.'¹

Rejection in an extreme form is advocated by the exclusive ideology of fascism. The glorification of the 'perfect' human being resulted, under Hitler, in an effort to exterminate disabled people altogether as 'imperfections which contaminate the genetic stream'. The Nazi Euthanasia Programme saw disabled people as 'useless eaters'; that is, they were perceived as making no contribution to society, and as a drain on resources. But Hitler was not the first to advocate getting rid of disabled people: in medieval Germany Martin Luther strongly endorsed the killing of disabled babies as

'incarnations of the devil', and many centuries before him the Spartans insisted upon it by law for the same reasons as Hitler. And the Nazis were themselves following the Eugenicists, English Victorian scientists of the nineteenth century who, influenced by Darwin, held that 'survival of the fittest' required the elimination of 'defectives'.²

It is perhaps tempting to assume that the world has moved on from such crude and overt rejection. But have we really moved? The Nazi doctors declared at the Nuremberg Trials that they were doing no more than doctors everywhere did, but without official sanction. Nowadays, when market forces are the dominant factor shaping social policies, it is not uncommon for doctors and health planners to argue that 'the country cannot afford too many disabled people'. The medical profession and planners of health services are ambivalent about the wonders of modern medicine: it can prolong the life of, for example, a person with spina bifida, but at what cost to the exchequer? And what if they have children? Who will pay for the consequences?



Muhammed, a blind person in the village of Unguja Shangani in Zanzibar. Disabled people experience rejection in all societies.

Social Darwinism and charity

There is no doubt that the allocation of financial resources in health is a complex matter, beset by profound ethical dilemmas. But an approach to health care guided by nothing but economics is not a great improvement on the nineteenth-century Eugenicians. And what about education? Transport? Housing? Are all these going to be planned in a way that says it is too expensive to cater for disabled people? The Nazis and the Eugenicians may belong to history, but today we have 'social Darwinism': the (usually unspoken) assumption that only the fit and the fully functional have a right to real life. It is this attitude that lies at the heart of the discussion on the politics of disability.

The Nazi and fascist vision of society is one based on the glorification of health, fitness, perfect specimens, and uniformity. In this vision, being different calls for rejection. At the other end of the spectrum is a vision of society based on a celebration of the whole diversity of creation, in which individuals are valued for what they are, not rejected for what they are not. Which of these opposing visions do we prefer?

It is unlikely that paid-up fascists will read this book. Can the rest of us then be excused from reading further on the politics of disability? I'm afraid not. There is the matter of charity. The 'charitable' approach to disabled people is also a form of rejection that is actually more insidious than fascism: it turns disabled people into objects who only receive and who do not participate in the processes which shape their lives. It sees them as individuals, with individual problems: according to the 'charity' approach, if you solve the problems of individual disabled people, then the 'problem' of disability is solved.

Except that it isn't. The 'charity' approach is more damaging than rejection as a cause of oppression of disabled people today, because it is more prevalent; with charity the assumption is that 'the problem is taken care of'. Out of sight, out of mind. It is assumed that if disabled people are looked after in separate institutions or by separate services, then that is OK; it may not be ideal, but it is better than nothing. But apart from whether institutions are humane or not (and some certainly are), or the effect they have on disabled people, there is the question of human and financial resources: in India there are an estimated 15 million disabled children requiring education, but existing institutions cater for about 100,000, or 0.6 per cent. Charity cannot cope.

The 'charity' approach grows out of social Darwinism: as long as the underlying assumptions about society are shaped by notions of 'perfect' and 'imperfect', there will always be a need for someone to pick up the pieces, the 'imperfect' pieces. But there are more such 'pieces' than can ever be picked up in this way. If disability is seen as an individual problem, services will always be inadequate, because individual needs can never be fully met.

The crucial distinction that has to be made is between universal rights and individual needs. Charity is about attending to individual needs; what disabled people want is for their rights as ordinary citizens to be recognised. Both able-bodied and disabled people are caught up in an unquestioned attachment to the charity model, often in very subtle and unrecognised ways, and both need to break out of it because, in the final analysis, it cannot deliver.

The dilemmas are the same in both developed and developing countries. Sheer survival in very poor countries like Sudan also poses major ethical dilemmas for decision makers. **Muhammed Osman** describes vividly how attitudes and decisions shaped by social Darwinism operated in Sudan during the famine of 1983-84. His home town of Nyala became a major food-distribution point:

It was famine, and I live in Nyala, over 1,000 km from Khartoum. People were dying at that time of starvation, and people were moving from neighbouring Chad or northern Darfur to southern Darfur, so Nyala became a meeting point for many different people. And you could see that in this situation disabled people were becoming victimised. Always disabled people, women, children, the elderly, are left behind when it comes to survival. Only the fortunate ones were able to come to Nyala.

Not only were disabled people not able to reach Nyala, but many of those who already lived in the town could not stand in the queues at the food-distribution centres. In the last chapter we saw how Muhammed discovered his identity as a disabled person through learning that his condition was incurable, and that with this discovery he determined to work with other disabled people. There was no movement or organisation of disabled people in Sudan, let alone Nyala, at that time. He was uncertain what he should do. The famine provided an opportunity. He approached the representative of an aid agency which was donating relief food, and explained the problem faced by disabled people:

The aid agency rep. said, 'Well, first of all, who are you? Whom do you represent? We have an agreement with the government of Sudan to distribute food according to certain rules; you know, we give it to councils, or district committees, and this is the way we have agreed to do it. If you have any complaints, you go to the government.'

So Muhammed went to a government official:

Now it happened that the one who was in charge of food distribution in what they called the technical committee there in Nyala was an old school mate of mine. I remembered him well. So I went to him and asked, 'Well, what are you going to do for disabled people??' He said, 'What's the problem?' I replied, 'We can't come out and queue.' He said, 'Well, you're complicating things; if we make an exception for you, the women will also say: "We want a special allocation".' I said, 'Yes, if there is a need, you have to think about it.' But he said, 'No, no, no, it is not in my power to do so, so please do not complicate these things.'

For Muhammed this was the second major trigger in the formation of his consciousness in the politics of disability. The first was when he assumed positively the role of a disabled person. Now these replies from officialdom made him aware that unless disabled people take action together, nothing will change; he recognised at this point that it was not an individual problem: if he approached it as an individual, nothing would happen. It turned out, despite its apparent negativity, to be the beginning of a process of empowerment for him and other disabled people in Nyala.

Private troubles or public responsibility?

Is disability an individual or a social issue? Is it a question of 'private troubles' or 'public responsibility'? Should decisions on disability be made on the basis of 'individual need' or 'universal right'? On the answer to these crucial questions rests all policy planning for disability, the training of professionals, the provision of services, the quality of life for millions of disabled people and of able-bodied people who will become disabled. Is disability an individual or social issue? It is *the* crucial question.

At the individual level there is the question of how the disabled person relates to his or her impairment, and that is conditioned, as we saw in the last chapter, by the attitudes of society towards disability generally. It is true that the way in which disabled people

feel about themselves will influence the way they are treated, as individuals, and it is true that social change has to start from disabled people. But the grave danger of pursuing that argument too far is that it places the onus back on the disabled person, when it really belongs in the public domain.

The bottom line is that disability is in the eye of the beholder, not in the eye of the person with an impairment. It is social attitudes which create the 'problem' of disability. It is not disabled people who create the problem. If that sounds too theoretical, consider the practicalities. The 'public responsibility' is created by currents well beyond the reach of the individual disabled person. Social, cultural, religious, economic, and political practices all play a part in creating disability and the negative attitudes that go with it. For example, impairment in the workplace may be created by shoddy safety standards resulting from a quest for maximum profits at the expense of humane employment. Once impaired, a worker may then lose not only income but also a role in life, self-respect through not being able to provide for a family, and respect within his or her community. The driving force which creates the impairment here is greed; the impairment is then turned into a handicap by an assumption that unless someone is productive, he or she is useless.

But society is composed of people. Society cannot change unless individuals change. A change in consciousness happens at the individual level, in both disabled people and non-disabled people. This change in consciousness consists in understanding that it is a social and political issue. Individuals on their own can achieve little.

What is empowerment?

Empowerment is a word much used in development circles. What does it actually mean? This is a somewhat murky and misunderstood area, and it is important to explore what we mean when we speak about the empowerment of disabled people (or any people who are oppressed and disempowered).

Politics is about the struggle to change power relationships. Those who hold power feel threatened by the idea of others being empowered, if it means that these others slip out of their control or, worse, challenge their own comfortable position. This holds true in the politics of disability just as in politics generally: those perceived as holding power are the professional carers and administrators, and the powerless are disabled people themselves. This was graphically illustrated in Winnipeg in 1981 (as described by Mike du Toit in the

previous chapter), at the 14th World Congress of Rehabilitation International (RI). RI is an organisation which principally represents professionals, but also service providers, government officials, and others involved in rehabilitation; disabled people may also be members. When the request by disabled participants for 50 per cent representation on the Board was turned down, it was a classic case of the professionals in power feeling threatened at the prospect of their position being challenged. The power of professionals in the rehabilitation business depends on disabled people remaining as passive recipients, not active participants.

But imbalances in power between disabled people and the able-bodied world are manifested in other forms too. Instead of vested interests being threatened, as in Winnipeg, there may be plain inertia, as in the example from Nyala quoted above: harassed officials, whether in famine-relief systems or in local councils, plead that they just do not have the time to grapple with what they perceive as yet another complicating problem. Or it may be argued that there simply isn't room in the organisational budget to make the extra provision for people with 'unusual' needs.

But does the process of empowerment need to be seen only in terms of winners and losers, a zero sum game in which if X wins, Y loses? There has to be a different way of viewing empowerment, one in which everyone wins. When the word 'empowerment' is used in development discussions, I submit that it is not the zero sum game that is being suggested. We are talking about a vision of society in which everybody ultimately benefits, not one in which some are dominant and others are oppressed. There is not much point in 'empowerment' if it means that the oppressed become the new oppressors.

In the case of disability, we are definitely not talking about that kind of pendulum swing, but about a change in power relationships from which everybody ultimately benefits. The present system, because it has grown out of the 'charity' model that is based on individual needs, cannot deliver. No matter how much power they may have, the professionals will never be able to see to the individual needs of all disabled people, at least not in developing countries. The only realistic option is for disabled people to take action on their own behalf. There is nothing inherently threatening about that; it simply makes sense from a practical and pragmatic point of view, apart from all other considerations. We are not speaking of an irrelevant or marginal rebellion, but of absolute necessity.

The process of empowerment

So how does empowerment happen? It comes back largely to attitudes. We can show the contrasting attitudes of people who are empowered and people who are not empowered like this:

Empowered	Not empowered
open to change	closed to change
assertive	aggressive
proactive	reactive
self-accountable	blames others
self-directed	directed by others
uses feelings	overwhelmed by feelings
learns from mistakes	defeated by mistakes
confronts	avoids
lives in the present	lives in the past or the future
realistic	unrealistic
thinks relatively	thinks in absolutes
has high self-esteem	has low self-esteem

The characteristics of an empowered person are immediately evident. Empowerment comes from these positive attitudes finding expression. But nobody loses by meeting an empowered person — quite the contrary. Disabled people need to see themselves and their roles positively, and they can be given the power to do so if other people relate to them positively. Does this mean that able-bodied people are somehow losing some of their own power? Not at all. In fact they are becoming more powerful, in the sense of more enlightened and more human, through the act of enabling a disabled person to feel empowered. This is where it is difficult to understand why medical professionals feel so threatened by disabled people becoming empowered. When the professionals grasp the point and work in a way that truly liberates the disabled person, they themselves are liberated. It's a pretty good feeling.

Venkatesh, in his explanation in Chapter 2 of how he works with disabled people ('my work is the development of human resources'), is following the ideas of Paulo Freire (developed in *Pedagogy of the Oppressed*).³ Freire introduced the concept of empowerment through what he termed 'conscientisation', that is, the process by which oppressed people come to understand the root cause of their own

oppression. Once such an understanding has been reached, they can begin to do something about it.

Outsiders can act as catalysts in a complex process where the right environment for a change in consciousness is created. That catalyst role is sometimes unpredictable. The aid agency official in Nyala was presumably not even thinking of empowerment when he asked Muhammed, 'Whom do you represent?' But his question acted, unwittingly, as the trigger for a shift in consciousness in Muhammed that was itself empowering.

How consciousness is changed is indeed unpredictable, but there are certain common themes in the experience of disabled people which provide pointers for a strategy. 'Whom do you represent?' is the key question. As an individual, Muhammed represented no one. The need, he suddenly realised, was for disabled people to form themselves into a group which could be recognised as significant, with its own voice.

So you see what happened ... at that time we were just beginning. Certain challenges were presented to us. In fact this man helped us a lot, because it was only then that we realised the importance of coming together. We realised that unless we could bring disabled people together and present a petition to a minister or something, nothing would happen. These people would do nothing to help us as individuals.

For millions of disabled people all over the world, isolation (both physical and social) is the main obstacle to this realisation. But once this isolation is broken, dramatic shifts in consciousness result. The case studies in this book supply many examples, mainly from rural settings, of the extraordinary empowerment that results from breaking the isolation of disabled people. The effect is not just in terms of changes in their consciousness, but in showing a far more effective way of dealing with the practical problems of disabled people than the existing 'charity' model provides.

Joshua Malinga is the Secretary General of the Southern Africa Federation of the Disabled (SAFOD) and the Chairperson of DPI (Disabled People's International). He is outspoken in his criticism of the 'charity' model:

Charity has not really solved the problems of disabled people. What it has done is that it has entrenched the negative attitudes; it has made the position of disabled people worse. Disabled people have not

benefited from charity, because charity is not part of the development process. It is not part of national socio-economic development. Disabled people want to be treated as normal citizens, with rights. They want to be treated equally and participate as equal citizens in their own communities. To achieve this, you need political and social action to change society.

It is to challenge the 'charity' model that Joshua believes that social and political action is necessary, and that is why there is a disability movement.

The need for a disability movement

The growth of the disability movement, which is a fairly recent development of the last two decades, flows naturally out of the kind of individual changes of consciousness illustrated in the preceding pages. **Rachel Hurst** of DPI found that her own personal experience led inevitably towards collective social action:

I've actually been disabled for most of my life, but when I became disabled in society's eyes, when I started using a wheelchair, I realised overnight that I wasn't, in society's eyes, the person I was supposed to be, or knew myself to be. So I immediately wanted to change the world to get them to think appropriately, and tried to do it myself, which was a complete waste of my time. It was a very salutary lesson that you can't do it alone. You can only do it by coming together with like-minded people and being very clear. When you come together with other disabled people, you have the time and the opportunity to discuss what the situation really is — what oppression is, who is oppressing you, where oppression comes from; what discrimination is and where it comes from.

Those are the issues which need to be discussed; and you as an individual cannot possibly see the light over all these issues on your own, and particularly if you are battling, as an individual, with starvation, segregation, and deprivation. You are actually much more worried about where your next meal is coming from than about the whole political thing.

The same story is told in different ways in virtually every one of the hundreds of interviews conducted for this book. We are not speaking of some kind of way-out political radicalism that can be dismissed as 'left-wing' or whatever. 'Left' and 'right' actually have nothing to do with it. It is a matter of the logical progression of ideas in a section of the population that has normally been denied any



A disability group in a village in Andhra Pradesh, headed by Ramu (centre) who has leprosy.

kind of self-awareness and self-expression, let alone social and political action.

A question immediately arises, however, over the logic of forming a separate group called 'disabled people'. If integration is the eventual aim, so that disabled people are regarded as nothing unusual and are accommodated as a matter of routine into the affairs of everyday life, then surely forming a separate group runs counter to that aim?

Segregation is when people are kept apart — not through choice, but against their will. The crucial issue for disabled people is whether they have the choice to form their own groups. 'Being in the same boat, knowing what it is like, sharing experiences, and helping yourself by helping others all add up to a fellowship that is the key feature of self-help groups.'⁴ It is that choice, the possibility of forming common-problem groups with the rich sense of fellowship which they bring, that marks the beginning of empowerment for disabled people, as we shall see in detail in the country case-studies.

Creating a movement

Fellowship in disability groups is one thing. But there is a need to go beyond fellowship and take on the question of advocacy, to create a

movement. As Venkatesh said in his interview, an ideal world would regard disabled people as nothing out of the ordinary, and there would be no need for a separate movement. But in the very unbalanced world in which we live, run by the comfortably-in-power as well as by well-meaning but harassed officials and administrators, there has to be a separate movement struggling to make its voice heard. **Nawaf Kabbara**, a founding member of the Friends of the Handicapped in Lebanon, explains the dilemma, which was particularly acute over the organisation of the peace march by disabled people in Lebanon in October 1987:

This is a discussion that is going on all the time. There is much misunderstanding. There is a process to be taken. When you are managing a life outside society, you have to make society aware that you are there. Only then can you be integrated into society. We have hardly started the beginning of this process. I mean, you can't be integrated if you are not even recognised as being there! This is what people do not understand. I have been challenged on this many times in Lebanon. Over the peace march, they accused me of trying to use disabled people for political purposes. But this is the way for people to see that we are there. That we exist.

Joshua Malinga, who attracts the same kind of criticism, echoes this:

If you see yourselves as a minority and as a group that is not taking part in society, you have to find a solution, and one of the solutions is that you organise as a group to create a voice, and then you get listened to by the powers-that-be.

But once this awareness has been reached, itself a major milestone, the path that lies ahead is very tortuous. Because of their isolation, disabled people tend not to have had practice in even the rudiments of a democratic process. It would be unrealistic to expect people who have had little or no education, who are unable even to meet with people in the next village, and who have never been involved in a decision-making process, suddenly to acquire all the skills needed to form and run an organisation aiming at major social change. It is one thing to realise the need for a movement, quite another to form one which is dynamic, democratic, and effective. The next stage in the events in Nyala, described by Muhammed Osman, is instructive here:

At the beginning we were a group of nine who set up the Nyala

society. Now there are differences. At the beginning there was nothing that people could argue about. But once there is an office, a vehicle and some sort of funding, once you come to tables and desks, then there is something to argue about.

The early excitement of beginning to feel a sense of empowerment through acting together was dampened by the reality of trying to run a democratic organisation. Muhammed recalls that once they had established themselves as a group and scored a first success in persuading the officials to make provision for disabled people in the food distribution, they then had to sort out their own distribution principles and priorities.

I chaired the committee which was to decide on the distribution, and I realised how undemocratic we were: just a group of nine were asked to set the terms for distributing the food to our own members. Now from the group of nine there came voices that we on the committee should get two bags each and give the others one bag. I asked why, and the excuse was that the others would not have got any food, had it not been for us.

So much for equality and justice! Muhammed goes on:

So I said, 'Look, what are we going to say to the members? Are we going to say that we take two bags and you take one simply because you are not on the executive committee? This means that seats on the executive committee are privileged.' But they were adamant. In the end I refused, because it was quite clear that we were inviting problems.

Muhammed was in a lonely position. But he had one other person who was committed to fairness.

So I said to myself and to the person who was with me and supported me, 'We need to find a way round this.' So at the next meeting I suggested, 'Why shouldn't we set up sub-committees? So that the social secretary sets up a social committee, and instead of just being on the Executive, he has to represent that committee. So that at least the decisions in the social sphere are not taken by only one person.' The point is, we needed to democratise the whole thing. By having nine people elected every two years, we were giving power to a group of disabled people at the expense of the others, because once they are in power, they cannot be challenged.

A common criticism of disabled groups is that they tend to squabble among themselves; it is implied that because they are disabled, they should somehow be above normal human behaviour. But normal human behaviour, when big issues like social change are at stake, is frequently unedifying; one only has to listen to a debate from the House of Commons in the British Parliament to be reminded of that. And development agencies themselves are notoriously fractious. Being democratic is an immensely arduous process that takes years of experience and a sophisticated ability to grasp complex and entangled issues. It does not come naturally and is not learnt in a day.

It is important to stress at this point that part of the process of empowerment for disability groups is to be allowed the freedom to fail. If failure is not a possibility, that is, if others come to the rescue too often, then it is unlikely that much of substance will be learned. A sustainable organisation is one that has learnt from its failures. Muhammed Osman is very open about the difficulties that face the movement in Sudan, which are the same issues that face disability groups — or any social action groups — everywhere. A common difficulty is leadership: it is frequently the case that disability groups are led by disabled people whose own consciousness, sense of the issues, and ability to articulate them owe a good deal to educational opportunities not enjoyed by others. In other words, leadership tends to come from an elite. In Muhammed's case he was the only one in the group with a university degree and good English, which gave him access, for example, to the powerful world of aid-agency representatives. He therefore came to be perceived by the group, despite the role he played in setting it up, as 'one of them' rather than 'one of us', especially when he had to challenge their plans for an unequal distribution of food. The principal need, in his view, is to be very clear about why the organisation is being set up and what its objectives are:

The first thing we have to do from within our ranks is to agree what we want to do through this organisation. I mean, we disabled people have to ask ourselves frankly why we are setting up organisations of disabled people. Is it just to sit in committees, or is it a means to an end, which is social change, by which I mean changing attitudes? Because we are individuals in our own communities; disabled people themselves need to understand why the community is behaving like that, and the community needs to understand why disabled people are behaving like that. Now we as disabled people have not yet reached that level of understanding.

Then there is the question of their own prejudices to deal with, just as in the world of the non-disabled:

In our meetings we often just beat around the bush; we raise the issues, but we never settle them. We say, for example, that the community discriminates against disabled people, but we disabled people also discriminate against our own disabled people. For example, the representation of the blind is not as it should be, nor of the deaf, let alone the mentally retarded. The challenge to the disability movement is how to overcome this.

Yet another problem to be faced is how far disability groups interact with mainstream political parties. In the Nyala case, starting with such enthusiasm and, it must be said, innocence, it suddenly dawned on the committee that they were entering the political arena. What would that mean? It came up in the context of having to register the organisation with the Ministry of Social Welfare. Muhammed explains:

So I discussed it with the group, and they said, 'Well, we've never heard about this Ministry of Social Welfare; we should go to them.' But one of the members raised the point that doing disability is doing politics. At that time it was Nemeiri's regime, you know, a one-party state, and there was the problem of how to operate outside the party system. Because there was a rumour that the Sudan Socialist Union was trying to bring us into their party.

This is an increasing difficulty in Sudan. It is possible that the formation of self-help advocacy groups like the one in Nyala is possible only in a country where there is at least a degree of official tolerance for this approach to development. This rules out some countries in Central America, for example, where even to be a rural health worker is to risk your life, and animation of communities is quite out of the question.

In countries where there is some form of democracy, a further consideration for disabled people working on the political level is whether to involve themselves in mainstream politics. Both Joshua Malinga and Nawaf Kabbara, of those so far quoted, are city councillors in their home towns. In the country studies we will deal in greater depth with the practicalities and difficulties in the mobilisation of disabled people, in particular the difficulties of democracy and representation.

Integration, segregation, normalisation, and participation

We have already considered the question of whether a separate disability movement runs counter to the ideal of integration. From the viewpoint of the disability movement, this was answered in the previous section: you cannot ask for integration if people are not even aware of your presence. If integration is the aim, the problem is how to get there. There is also the question of integration within the disability movement: Muhammed Osman mentioned the problem of how to integrate those with communication impairments like deafness into the disability movement, which tends to be dominated by the conventionally articulate.

Communication-impaired people pose a double problem for integration: they find themselves excluded both from non-disabled society and from the disability movement. It is rare to find deaf people, for example, as leaders of cross-disability groups. Deaf people are frequently excluded from educational opportunities, and go unnoticed because their impairment is not visible. They are heavily dependent for their education and information on hearing



Like many deaf children, Fadwa — who lives in a refugee camp in Gaza — has been denied educational opportunities. But now, aged 13, she is making good progress at a neighbourhood disability centre. Here she is working with Shafiq al Bis, a volunteer helper.

people, who are in the role of 'benevolent oppressors'. With access to communication through sign often denied, and poor oral/verbal skills, how can they assert themselves? I attended an all-Africa DPI conference in Zimbabwe in September 1991; the organisers had made no provision for interpretation in sign language; a speech-impaired lawyer in Zimbabwe who has offered his professional services to the disability movement has consistently been refused. Deaf and speech-impaired people, because of their lack of oral/verbal language skills, and in spite of physical 'able-ness', go to the bottom of the power ladder. It is oral ability which carries power.

The words 'segregation' and 'normalisation' raise all sorts of questions. Should disabled people be treated as though they are not disabled, or should their disability be recognised? On the one hand, disabled people seem to be saying: 'Don't treat us as anything unusual.' On the other, they seem to be saying: 'It's not us who have to change: it's society that must recognise us and accommodate us.' It is exactly the same issue that confronts any social action group advocating its rights as a minority. How far do you 'normalise' and how far do you remain segregated? Because they tend to be excluded from both non-disabled society and from the disability movement, deaf people in particular have created their own culture and communication system which gives them a distinct identity. Deaf people are proud of their deaf culture with its own language, and many deaf people would say they do not want to be viewed as 'normal'. And yet obviously oral communication is very important for their own development, and written language even more so. So the answer lies in 'bi-lingualism', with ability to relate to both worlds.

Lessons from the Peto Institute

The issue of normalisation comes into sharp focus through the experience of Vic Finkelstein, a wheelchair user who teaches a course on disability through the Open University in Britain and who was one of the first people to become active in the politics of disability in Britain. In an article in the journal *Therapy Weekly*,⁵ he described a visit he made to two cities with very different approaches to disability: Budapest and New York.

New York is a city which has a policy of accessibility for all public buildings and buses; in consequence wheelchair users are a familiar sight in the city, and are thus half-way to being socially

integrated. In dramatic contrast, in the Hungarian city of Budapest there are no ramps on pavement kerbs, and neither public buildings nor public transport are accessible to wheelchairs. The policy in schools is that if a child wants to attend, he or she must be able to walk. The result is that disabled people in wheelchairs are not seen at all on the streets of Budapest. Those who cannot walk are stuck at home, presumably living out a kind of twilight existence, because they cannot go anywhere without an enormous effort and a great deal of help. They certainly cannot go anywhere on their own.

In response to the situation of Hungarian children with cerebral palsy, the dedicated staff of the famous Peto Institute in Budapest work 8 or 12 hours a day in efforts to teach them to walk, through a process known as 'conductive education'. 'Normalisation', in the sense used in the Peto Institute, sets out to make disabled people as much like non-disabled people as possible, so that they can fit into 'normal' society. And that is indeed what many disabled people and their families would like, especially the parents of children with cerebral palsy who are willing to make enormous sacrifices for their children to be taught to walk by conductive education; there is now a vigorous parents' campaign in Britain, for example, to set up such centres across the country.

It may well be right for individual children with cerebral palsy to learn to walk, rather than use a wheelchair. It undoubtedly does a great deal for children's self-esteem and self-confidence to be on their feet, especially if the only option is being stuck at home staring at the ceiling. There is nothing wrong with conductive education in itself. But where Budapest has got it wrong is that it insists on normalisation — and the Peto Institute endorses this insistence.

Such a policy is highly detrimental to the interests of disabled people in Hungary generally. It stands as the ultimate example of the 'cure or care' approach: parents come to the Peto Institute in the hope that their child will be 'cured'. But in terms of physical rehabilitation, techniques like conductive education can only do so much: they cannot produce a complete 'cure', and there will always be those who are in wheelchairs whatever therapists can do. The point is that disabled people themselves must decide what normalisation means for them as individuals, and how far they want to go along that road. What is unacceptable is for an entire rehabilitation policy to be founded on the insistence that 'disability must be overcome' if disabled people are to benefit from what is on offer to 'normal' people. To throw all of a country's resources into

professional efforts of this type, with no awareness of the need for creating a barrier-free environment in the country at large, is tragically misguided. It is obvious that for developing countries the Peto model, even if it were possible, would be an irresponsible and unrealistic use of scarce resources.

The point at issue is whether disability, represented here by wheelchairs, is accepted as an ordinary part of human existence, or whether it is so unacceptable, threatening, and inconvenient to able-bodied people that disabled people are allowed to join in life only if they play by the rules of able-bodied people with all their functions. Integration means opening up social structures and attitudes to include disabled people, not changing disabled people to fit in an able-bodied society. There is richness in diversity. A society in which 'deviants from the norm' are rejected is not only repressive; it is also exceedingly dull.

A further key concept is *participation*. Much disability literature speaks of integration as the ideal, when in fact participation might reflect more accurately what disabled people aspire to. To take the example of deaf people again, they would like to retain their identity as deaf people, but they also want to participate in the non-disabled world. They certainly want to participate in the decisions that affect their own lives.

Society cannot change unless individuals change. The women's movement has had an effect on men: more men are prepared to listen to and understand the women's point of view, to exchange roles with women, to recognise the central importance of the feminine in the whole of life. It is possible to speak of the 'transformed man', the one who has gone through a quantum shift in perception on gender and come out the other side a very different person from his previous personality. So with disability. For 'men', read 'able-bodied people'. The disability movement is slowly creating changes in consciousness among able-bodied people who recognise the importance of what disabled people have to offer. Disabled people do not want to be seen as heroes, or as saints. They just want to be treated as human beings, and this realisation is gradually gaining ground among able-bodied people.

Disability and development: the basics

'Development is not something done to one lot of people by another.'
(Diane Auret¹)

Why is disability a development issue?

There is a close relationship between poverty and disability: malnutrition, mothers weakened by frequent childbirth, inadequate immunisation programmes, accidents in over-crowded homes, all contribute to an incidence of disability among poor people that is higher than among people living in easier circumstances. Furthermore, disability creates and exacerbates poverty by increasing isolation and economic strain, not just for the individual but for the family: there is little doubt that disabled people are among the poorest in poor countries.

However, it is important to stress two vital points that contradict much received wisdom on the prevalence of disability. The first is that impairment is not only a function of poverty, and is not restricted to poor people. An important factor is cultural behaviour, such as early marriage in India, female circumcision in Africa, or marriage between blood relatives in the Middle East. Wars, which since 1945 have taken place chiefly in the South, have maimed hundreds of thousands, mainly civilians, irrespective of class. Disability affects all strata of society.

The second point is that more technical development does not mean less impairment. Statistics on disability are extremely unreliable but, while the *incidence* of impairment may be high in

developing countries, there is strong evidence to suggest that improved health care in industrialised countries leads to increased *prevalence* of impairment, simply because those with severe impairments survive longer, and people live long enough to acquire the impairments of old age.² ('Incidence' refers to the numbers of cases which actually occur; 'prevalence' refers to the numbers of people who survive.) Thus disability is also an important development issue in industrialised countries. (We will examine the question of numbers and statistics more closely in Chapter 7.)

The profile of impairment types changes with medical advances and demographic factors: polio may have been virtually eliminated from most countries, but, as people live longer, the impairments of old age such as cataracts and arthritis come into play. The proportion of disabled people in industrialised countries now is therefore probably higher than it was in the nineteenth century. Disability cannot be eliminated by medical advances; medical advances simply change the proportions of various impairments in the population.

I am not trying to diminish the importance of the discussion about disability in developing countries. On the contrary, what I am saying is that this is very much a development issue shared by the rich North and the poor South. The age-range of disabled people in



Leprosy is a disabling illness associated with poverty. Ramu's husband has left her because of her leprosy, but she is a forceful member of the disability association in her village of Dampetla in Andhra Pradesh, India.

industrialised countries is weighted towards the later years of life, while in the South disability tends to occur in the earlier, productive years. Society, whether in the North or South, therefore has no choice but to come to terms with disability as a part of life.

An analysis of disability based on poverty alone is not only inaccurate; it is also misleading, because it somehow puts disability 'out there', whereas it is very much 'in here', close to each of us. Disability is a major feature of life in both developed and developing countries, and can affect anybody of whatever background at any time. Nobody is immune, and nearly everybody is likely to experience disability personally or through a family member or close relative to some degree at some point in their lives. Disability is therefore not a separate issue from which we can choose to remain detached: it is woven into the fabric of all our lives, whether we like it or not.

This works both negatively and positively. On the one hand, the realisation that disability can affect anyone may make people more afraid of it; on the other hand, greater familiarity in industrialised countries has led to a greater awareness. In some countries there has been progress in making significant changes to give disabled people an equal chance through, among other things, legislation, adapting the environment, and mainstream integration of disabled children. There is still a long way to go, especially in the way in which the whole medical world relates to disability, and books like Colin Barnes' *Disabled People in Britain and Discrimination*³ make it very clear that institutionalised discrimination is still the norm in countries like Britain. But the process has started. Disability is on the map.

Official assumptions about disability

In developing countries the scene is less encouraging. Development policy in the South is formulated by governments and international agencies, and both tend to give disability a low priority in overall development planning. But that is not to say that nothing is done about disabled people: there is a huge industry based on disability, especially among private voluntary agencies — and that in itself poses another set of problems. According to Rachel Hurst, 'There is a vast network of medical, charity and social work experts who have, as it were, cornered the market in disability.'⁴ Disability is big business, but it is in the hands of the wrong people.

The disability 'industry' is driven largely by attitudes that are more 'charitable' than 'developmental'. It is rare to find disability

being considered systematically with developmental attitudes by development planners at the level of governments or international agencies. It is worth looking at some of the arguments used by planners in development when they are challenged on disability:

- Rehabilitation is complicated and expensive, requiring trained professionals; it is beyond the abilities of ordinary villagers.
- Aids and equipment for disabled people are too expensive to be budgeted for in normal primary health care programmes.
- If they survive, disabled children will become disabled adults who will be an economic burden all their lives.
- Disabled people are taken care of in institutions; there is a whole industry to cater for them, with millions of pounds poured into it, mainly from private sources; 'real' development is about empowering people to help themselves.
- Disability is not a priority when so many children die before their first birthday anyway of such causes as diarrhoea; let us bring down the infant mortality rate first, and then we can think about things like disability.

Underlying all these arguments is the undeniable influence of social Darwinism, with the implication that unless a person is 'normal', he or she does not qualify for the same chances as everybody else. But these arguments are based not so much on prejudice as on ignorance and a lack of awareness of what is possible. The country studies in this book illustrate that rehabilitation can be effectively practised by uneducated people; aids and equipment are not always complicated or expensive; and disabled adults do not need to be an economic burden.

As for institutions, we have already seen that they can cater for only a tiny fraction of disabled people in developing countries: it is precisely the inadequacy of this approach that demands a different way and the integration of disability into the heart of the development process.

As for the last argument, we must ask when can the infant mortality rate be considered low enough to move on to dealing with disability? When it reaches 100 per 1,000? 90? 50? Who is to say? The idea of 'solving' one problem in this way before moving on to another is in any case misleading and unrealistic in development terms: not only are problems of this magnitude seldom solved in

such a discrete manner, but this argument implies a materialistic and mechanical approach based on dealing with faceless masses of human beings with no individual identity and no say in their own lives. It is implied that it is the development agencies' or governments' job to reduce these figures. 'Development' becomes a kind of numbers game in which the appalling indicators of underdevelopment must be reduced — by people making plans in offices.

Fertility control and self-determination

There is no question that the infant mortality rate must come down, and there should be fewer babies born in the first place. But how can these figures be reduced? If people feel they have some control over their lives, they are more likely to make responsible decisions. The evidence points to an improvement in the quality of life, coupled with a greater sense of being able to take decisions over the factors which influence one's life, as the most effective way to bring the birth rate down, not mass sterilisation campaigns. The best way to improve the quality of life is by focusing at the community level and giving people a real voice in the decisions that affect their lives. Once people feel they have some control over their immediate concerns and are not just ciphers in someone else's plans or hostages to an unknown and fickle fate, then their whole attitude to themselves, their children, and their future becomes more hopeful and more structured.

This is an important point. It is often said that having many children is an intelligent response to the conditions in which people live in developing countries, because children provide some kind of security in old age. The interviews conducted for this book give the lie to this view: many people in villages in Zimbabwe, Zanzibar, and India said that having many children made poverty worse; they argued that the problem of inheritance is greatly exacerbated by large families: they expressed the view that the increasing division of land leads to increasingly uneconomic plots; two educated children are more likely to be better off than six who have had little or no education; therefore two children are more likely to take care of their parents than six or seven. A number of elderly disabled people interviewed said that their children were not looking after them, and that it was a mistake to rely on them.

I stress this point partly to question an assumption that seems to have become enshrined as a dogma in development doctrine (that having large families makes economic sense to the parents), and

partly to stress that community development has much to do with hope, and with people feeling that they have some control over their lives. Having many children seems, according to the testimonies of the scores of people I have interviewed, to be a response more to uncertainty than to hope, a reaction to an unknown fate and a future which they do not in any way control. But once people begin to feel they do have some say in their future, then they take more rational decisions — and this is reflected in having fewer children.⁵

Action on disability can enrich the whole community

Positive action on disability is an important part of the process by which a community gains more control over its life and more hope about its capacity to solve immediate problems. So to see work on disability as drawing resources away from other aspects of development, or as deserving a lower priority, is to miss the point of what development is actually about. Work on disability raises levels of community responsibility and civic consciousness; ignoring disabled people simply perpetuates despair and hopelessness in the whole community, not just for disabled people and their families. It is very rare to find a parent who does not want to do the best for a disabled child; neglect is not usually wilful, but often the only option when no services are on offer: as soon as some kind of service is available at community level, there is always a flood of applicants to use it. In Jordan, the West Bank, and Gaza Strip the experience of starting neighbourhood centres for disabled children in refugee camps shows that the presence of such centres provides a source of pride and raises morale in the whole community, not just for those who directly benefit. The truth is that people operate more effectively when they feel valued and are able to value each other.

Development is not simply about finding a solution to the problem of poverty on the grand scale. Poverty is a symptom of a greater malaise, an intrinsically flawed materialism which fails to value the earth and its resources and all the people who live on it. Poverty cannot be 'solved' using materialistic attitudes and mechanisms. Disability provides a key to unlock the secret of where the deeper values lie; it challenges all of us over our fundamental attitudes to what determines the value of life. A society which ignores its disabled people or shuts them away in institutions

... is deprived of its necessary corrective. It mistakenly believes that only the disabled are dependent persons. It fails to see that

society itself is invisibly dependent on the disabled for a critique of its humane norms and values. In view of both our domestic social problems and the problems of the world community (for example starvation, apartheid and the gap between rich and poor), it is becoming ever clearer that the solution to these problems depends less and less on power and money and increasingly on the challenge of a radical thinking, that is learning.⁶

Disability is a development issue because it dehumanises. It dehumanises because, on the practical level, disabled people are left out of development planning and their voice is not heard in decision-making circles. On the philosophical level we know instinctively that if we deny the humanity of another, we ourselves are dehumanised.

We who have disabled friends, family, or workmates owe to them our affirmation of the value of their lives. It is for us to show the

'... the contribution that any infant can make simply by being alive ...'. A rehabilitation session for mothers and their children born with cerebral palsy, Harare Hospital, Zimbabwe



Photo: Chris Johnson/Oxfam

achievement of the disabled life, but more importantly the enriching contribution that life can make to the community.

It is a great mistake to believe that one can only contribute to society in the active physical sense. After all, what we do in the office, the home, the factory, is ephemeral, whether we do it as an able-bodied or a disabled person. What counts is what the great philosophies and religions of the world are all agreed upon, and that is the spirit of man. It is this that gives worth to what is basically the daily grind.

It is not enough to say that in extinguishing the life of the blind infant we may be destroying a Milton, or an Einstein in a deaf one. In extinguishing the life of any infant we are denying the world the contribution that infant can make simply by being alive, by laughing and loving, hurting and needing, simply being a human being.⁷

The contribution that disabled people can make to a more holistic understanding of the world is enormous:

We have noted that many disabled persons — especially those who have managed to learn skills and lead fulfilling lives — have developed an exceptional 'view of the world'. They feel a sort of brother-and-sisterhood with other disadvantaged, exploited and oppressed peoples — the Earth's 'socially handicapped'. They are committed to working in their own different ways toward a fairer world, one in which the silent speak out and the weak grow strong by joining hands. They feel that all who are disabled should be given an equal chance. They would like to help in the rehabilitation of a socio-politically disabled Human Race on ecologically disabled Earth.⁸

Three models of disability

A model is a framework by which we make sense of information. For the sake of clarity we shall consider three models or approaches to disability: the traditional model, the medical model, and the social model.

The traditional model

The traditional model is the construct created by religion and culture in any society. In most religions and cultures, disability is seen as a punishment, or the result of ancestral anger or retribution by divine forces. Such beliefs are not confined to religions regarded in the

West as 'primitive'. Christianity is no exception: where it is mentioned in the Bible, impairment is linked with being unclean, an outcast, and/or possessed by demons. We have noted that Martin Luther, imbued with these ideas, recommended the killing of impaired babies. Such beliefs are still widespread in many parts of the world, both Christian and non-Christian. A blind person I interviewed in Madras, India, was refused entry to a theological seminary because, he was told, 'a priest must be without blemish'. The traditional model regards disabled people as unfortunate, different, 'blemished'.

The medical (or 'individual') model

In the West the traditional model based on religious and cultural attitudes has been largely replaced by the medical model, which is an extension of the same idea. The medical model views an impairment as an 'abnormality' — which assumes that there is 'normality'. An abnormality needs to be 'corrected', 'cured', 'overcome'. The medical model has value in certain contexts, but when it is used as the *only* model for approaching disability, it is seriously defective: based on the concepts of 'normality' and 'abnormality', it sees the human body as flexible and alterable and the social environment as fixed and unalterable: if a person does not fit the social environment, then that person — not the environment — must be made to change.⁹

In Chapter 3 we considered the question of whether disability is an individual or a social issue, and concluded that any approach to it has to start with the understanding that it is primarily a social issue. The approach to individual disabled people has to be within a framework of understanding the whole social context of disability. The problem with rehabilitation based on the medical model is that it focuses on the individual, without relating to the overall social and environmental context. For this reason it is sometimes referred to as the 'individual model'.

The example of Budapest quoted in Chapter 4 is relevant here. The obstacles to disabled people's development in Budapest, at least those with mobility impairments, are the physical barriers imposed by a society that either has not understood or is dismissive of their needs for mobility. The rehabilitation model in Budapest evident in the Peto Institute represents a struggle to fit disabled people into a society which makes no allowances for them: if children want to go to school, they must learn to walk. The Peto Institute is endorsing

the barriers set up by this model through its efforts to get children with cerebral palsy to walk at all costs. This is the logical conclusion of the medical, individual model.

A rehabilitation model is needed which does not accept and endorse the barriers placed in the way of disabled people by society, but breaks them down.

The social model

The social model of disability starts from the point that integration is ultimately about removing barriers, not 'normalisation', cure, or care. Rehabilitation conducted within a comprehensive social framework is about the removal of barriers at the individual level; it is also about the removal of physical and attitudinal barriers in society at large. This book is, in general, an exploration of the social model.

Both able-bodied professionals and disabled people are caught up in the medical model of rehabilitation, largely because this model is only now beginning to be questioned, and the vast majority of disabled people and professional therapists have never known anything else.

The role of the professionals

This is a difficult section to write. I am aware that many of the people who will read this book are professionals working in the field of rehabilitation who are interested in development as an issue. They are therefore likely to have progressive and open attitudes towards their work, and to have moved away from a narrow devotion to the individual medical model. Many rehabilitation professionals in developing countries work in this way with an increasing willingness to welcome a partnership with disabled people in planning and delivering services. Growing numbers of disabled people themselves are becoming professional therapists and carers.

Nevertheless, a book like this would not be complete without taking a critical look at the role of the professionals, for two reasons: first, the medical model is still dominant in the West, despite a minority of professionals who have moved on from it; and second, training in developing countries tends to follow Western models, with all their inappropriate attitudes. It is also the case that a great deal of Western funding for disability projects in developing countries is directed at the medical model run by professionals wedded to it. The

rehabilitation industry is dominated by such professionals.

There are two fundamental points. First, nobody is arguing for fewer professionals: let us be very clear about that. They are vital. What is at issue is the underlying attitude they bring to the job. What disabled people want is to join with professionals in formulating policy on rehabilitation, and then to work with them to implement it. This is an exciting, positive process which in no way detracts from or undermines the importance of the professional task; on the contrary, it enhances it.

Second, professionals, from orthopaedic surgeons to occupational therapists, are needed in order to give disabled people choices about how far they wish to go along the road of 'normalisation'. If, for example, a disabled person has difficulty holding a cup, there may be two solutions: change the design of cup, or operate on the hand. If there is no orthopaedic surgeon, there is no such choice.

Agents of social control?

However, despite these points it remains true that many people in the disability movement see the control of their lives by rehabilitation professionals as one of the main causes of their oppression. Why? The oppression, in their experience, derives from two things. First, an attitude of 'cure or care' which sees them as everlasting patients: if they cannot be cured, they must be cared for. In the words of **Joshua Malinga** from Zimbabwe:

The point is that they believe that they have solutions to our problems. They do not see us as belonging to society, they think we belong to them, they have to keep files on us throughout our lives, and decide when we should see the doctor and so on. But I want to decide when I see the doctor! They have enjoyed power and control over us for a long period. We have to understand that we are talking about an attitude here. Changing attitudes is a very difficult thing.

Second, the 'success' of professionals working with the medical 'cure or care' model depends on disabled people co-operating in the process of treatment or cure, 'to get better at all costs', to return to productive function. But this approach is devastating for disabled people because, if it fails (that is, if it does not return them to productive function and leaves them 'disabled'), the implication is that, because they are unproductive, they are classed by society as non-people, people who have nothing to offer, rejects. It is hardly surprising that disabled people find such an implication

dehumanising.

Professional rehabilitation therapists are generally well-meaning and committed people: they are not blatant agents of social control, and do not sign up for their jobs with the intent to oppress disabled people. So what has gone wrong? They are obviously part of a bigger problem which is above and, in a sense, beyond them as individuals, an oppressive system in which they are unwitting cogs. This system can be analysed in several ways; for example, an historical overview of the development of capitalism would reveal the way in which 'being productive' has become crucial to defining a person's value; people are defined by what they do and what they can produce, not by what they are.¹⁰ Or an analysis from a religious perspective would show the development of the medical model from the traditional one. But whatever the historical reasons, what we have now, across the world, is a highly professionalised system in which trained experts relate to disabled people from a position of power and dominance, not equality.

In the industrialised countries this situation has provoked a crisis of confidence which sparked, most notably, the formation of Disabled People's International at the 14th World Congress of Rehabilitation International in 1981, already referred to twice in previous chapters. This momentous event drew the lines for the battle that has been raging ever since. Over the last decade there has been a major growth of organisations of disabled people across the world, which have certainly succeeded in some countries (Zimbabwe is a good example) in opening up the debate about disability, and in gaining recognition among people in power for the rights of disabled people. But the medical model is institutionalised, and institutionalised ideas are very hard to shift. There are also vested interests involved. Attitudes among professionals, the very group where a change in attitude is most crucial, have been slow to change, and there remains on the whole a deep division between organisations of disabled people and the professionals.

As specialists, professionals 'tend to diagnose a problem in relation to what they themselves can offer'.¹¹ Everyone is busy and formed by their daily experiences; it requires a huge imaginative leap to form a wider view. So policies, programmes, and projects are designed not only on the principle of 'cure or care' and 'returning to productive function', but also in a way which divides up work with disabled people into different professional tasks classed mainly under 'health'. There is a good deal of squabbling over professional

boundaries; trying to cross these boundaries, for example into education, then becomes very difficult, and amalgamating them almost impossible.

Professionals without a wider view tend to express a certain weariness about the hostility of the more militant disabled people towards their efforts, and may dismiss the disability movement and organisations run by disabled people as non-essential, a kind of extra for those who feel that way, with the implication that they should be jollied along, but not taken too seriously. They question the effectiveness of disabled groups, and point out that they tend to be fragmented. Similarly people who run institutions for disabled people, especially in the South, often see themselves as having a mission and living sacrificially in order to achieve it; the idea that they are oppressing disabled people would strike them as ludicrous, insulting, and profoundly ungrateful. (We will see a good example of this in the Zimbabwe country study.)

Thus the two sides are divided by mutual misunderstanding. Disabled people feel oppressed by the professionals, and the professionals do not understand why. But disabled people are very ready to acknowledge the value of professionals, and are quick to point out that developing countries have a severe shortage of therapists anyway, so control of disabled people by them does not arise in the same way as it does in the North. But unless therapists throughout the world begin to think differently about their role and see it within a wider social context, there is little hope of radical change.

The whole psychology of helping and being helped is a big and important subject: it is outside the scope of this book, but there are many excellent books which tackle it.¹² However, it may be useful at this point to hear the experience of one person (in the North) who was grateful for the therapy he received and had nothing but admiration for the therapists, but still remained profoundly dissatisfied:

I've been chronically ill for years. Stroke. Paralysis. That's what I'm dealing with now. I've gone to rehab programme after rehab programme. I may be one of the most rehabilitated people on the face of the earth.

I've worked with a lot of people, and I've seen many types and attitudes. People try very hard to help me do my best on my own. They understand the importance of that self-sufficiency, and so do

I. They're positive and optimistic. I admire them for their perseverance. My body is broken, but they still work very hard with it. They're very dedicated. I have nothing but respect for them.

But I must say this: I have never, ever, met someone who sees me as whole ... Can you understand this? Can you? No one sees me and helps me see myself as being complete, as is. No one really sees how that's true, at the deepest level. Everything else is Band-Aids, you know.

Now, I understand that this is what I've got to see for myself, my own wholeness. But when you're talking about what really hurts, and about what I'm really not getting from those who're trying to help me ... that's it: that feeling of not being seen as whole.¹³

Wholeness is the key. To be cast in the role of perpetual patient means to be seen only in part.

So what advice would an active member of the disability movement give to a young person contemplating a career as a physiotherapist? **Mike du Toit** from South Africa offers these thoughts:

I would certainly encourage them. I mean, particularly in my country we have such a severe shortage of people like physiotherapists. Of the few that there are, something like 80 per cent are in private practice, which means that they serve only the rich. A remarkable percentage work on horses! So obviously I would encourage them, but at the same time qualify that by urging them to have exposure to the movement of disabled people, and have their attitudes formed there, rather than in the professional circles.

And what does 'the movement' think the role of professionals should be? Mike du Toit again:

The movement does not reject the role of the professionals. What we reject is the inappropriateness of so much of the work that is being done, and the inappropriateness of their attitudes, and the complete inappropriateness of their seeking to represent us. We do need professionals, we need services, we need rehabilitation. But I would hasten to add that rehabilitation is something that happens to us for a very short period of our lives. It's by no means the most important thing in the life of a disabled person. But we need professionals, there is no doubt about that.

New skills and new relationships

The role of the professionals does need an overhaul. Fortunately there are very clear indicators of what is needed and how it can be done. The key word is *resource*: rehabilitation professionals need to 'change from management of the patient to that of being a resource for the disabled person to use in reaching their own goals'.¹⁴ This does not mean that professionals should become passive and de-skilled. Quite the contrary: acting as a resource actually requires a higher degree of skill than treating someone who is merely an object in the process. But it does require a different attitude and different training:

Professionals acting as a resource to be used by others need special education and training so that they are able to promote control by disabled people. ... To do this, professional workers will need new communication skills, new professional codes of practice, new ethics, new rules of confidentiality and new concepts of clinical responsibility. In all this the professional rehabilitation worker needs to learn how to listen to clients, while at the same time helping the client to identify the central rehabilitation issue. ... The need is for new relationships to develop between helpers and those they help.¹⁵



A new relationship begins in Jarash community disability centre, Jordan.

Such an approach will also ease the problem of professional boundaries and what disabled people see as the 'farce of professional teamwork', where they are shunted around from one professional to another, none of whom sees them as a complete person. If rehabilitation is a process controlled by the disabled person, and professionals are skilled resource people, then the whole context in which rehabilitation happens will change: the power balance will shift in favour of the disabled person, but without reducing the effectiveness or job satisfaction of the professional; rather, these essential elements will be enhanced. Working towards 'resource-based rehabilitation' is the major challenge facing both professionals and disability organisations.¹⁶

Ultimately the way in which professionals relate to disabled people depends on the image that professionals have of themselves. Ram Dass and Paul Gorman express it this way:

Implicit in any model of who we think we are is a message to everyone about who they are. It's not as if there are any real secrets. If we are seeing only one part of the picture about ourselves, positive or negative, that's all we will be able to make real to anybody else. Caught in the models of the separate self, then, we end up diminishing one another. The more you think of yourself as a 'therapist', the more pressure there is on someone else to be a 'patient'. The more you identify as a 'philanthropist', the more compelled someone feels to be a 'supplicant'. The more you see yourself as a 'helper', the more need for people to play the passive 'helped'. You are buying into, even juicing up, precisely what people who are suffering want to be rid of: limitation, dependency, helplessness, separateness. And that's happening largely as a result of self-image.¹⁷

Who needs rehabilitation?

For the sake of clarity it is useful to distinguish three main categories of disabled person: children; adults who have been disabled from childhood; and recently disabled adults. Each of these groups relates to disability in different ways and has different needs; in particular, their needs for professional input are different.

The needs of disabled children

Disabled children need focused rehabilitation and educational opportunities in order to maximise their potential and minimise the

effect of impairment. For example, a child with severe cerebral palsy, if left unstimulated and over-protected at home, will suffer even greater impairment, unable to sit up, feed herself, or play any kind of independent role. But if the parents are shown how to stimulate the child, to encourage her to use her limbs, and enable her, with supportive seating, to sit up so that her view of the world is not confined to a few square feet of the ceiling, then the effects of the impairment by cerebral palsy can be mitigated. Such an intervention needs a person trained in this kind of physical rehabilitation who can pass the necessary skills to the parents and other family members.

Similarly a deaf child, if left to cope without specialist care and discouraged from using sign language, may acquire hardly any language at all, with no tools for forming concepts, and may suffer serious intellectual impairment as a result. It is important for this child to have professional help at an early age, so that he acquires a means of forming concepts (either by signing or conventional language) as early as possible; otherwise his mental development will be impeded.

The needs of adults disabled from infancy

An adult disabled since early childhood or birth, if he or she has undergone some kind of rehabilitation process in childhood, will probably be outside the need for professional rehabilitation services, but may still have regular but probably fairly straightforward needs, such as checks on internal infections. Such a person's world view and awareness of disability issues are very likely to have been heavily influenced by the type and quality of the rehabilitation received earlier, if indeed there was any.

Both disabled children and adults disabled from their earliest years have always been part of the population marked 'disabled', and will probably have learnt to cope with the implications of that in various ways. Disability is part of their identity.

The needs of recently disabled adults

A recently disabled adult may have had feelings of fear and pity towards disabled people before being impaired, and may therefore find the whole experience of becoming disabled extremely distressing, with all the emotions of anger, rejection, and despair that are common when facing grievous loss. In particular, such a person may not want to be identified as disabled at all, as we saw in

Chapter 3 when considering ex-combatants. In analysing the biographies of 80 adults disabled since childhood, Erika Schuchardt at the University of Hanover found that 'two thirds of them remained at the stage of aggression, negotiation and depression and never reached acceptance; this results in a condition that is Oequivalent to social isolation'.¹⁸

Recently disabled adults definitely require professional rehabilitation, again to minimise the effects of the impairment and to maximise their chances of adaptation to the new circumstances. The presence or absence of good rehabilitation is a matter of life and death: the life expectancy for a spinally-injured black person in South Africa is about one year, in stark contrast to a spinally injured white person, who can expect to live many years. The difference is that the white gets proper rehabilitation, while the black does not, and will probably die from bedsores, urinary infections, and other complications.¹⁹

The point is well illustrated by a study of spinally-injured people in Zimbabwe carried out by Veronica Brand in 1984.²⁰ An earlier study had revealed that there was 'a very high mortality rate for paraplegics discharged into rural areas'. She set out to discover the reasons why, and found two main factors: first, there was almost no attempt at social work or preparation for life beyond the hospital; second, there was very little contact between the hospital and the family of the injured person during treatment, because the family could not afford to keep travelling to the city from rural areas. Thus even if there had been some attempt at preparation for returning to the village, the family could not have been involved in it. 'Lack of contact between relatives and hospital personnel, either in the form of family counselling sessions or through home assessment visits, contributed to a situation where discharge was likely to be a traumatic experience, both for the paraplegic and for the family.' Thus the family had little idea of the recently disabled person's needs or how to meet them.

Both disabled children and recently disabled adults have a profound impact on their families. Consequently rehabilitation needs to pay attention to the non-disabled members of the family members too.

Survival in such cases is not only a matter of avoiding bedsores and dealing with urinary infections: a paralysed person needs a reason to live, otherwise he or she may simply turn to the wall and die, seeing no point in continuing as a burden to their family and

themselves. The challenge is to help such people to identify skills that can be transferred from their previous lives, and also train them in new skills. For example, a quadriplegic man in Ain el Hilweh refugee camp in Lebanon has started reading books on to audio tape for blind students; he can't use his limbs, but he still has a voice.

Rehabilitation means removing barriers

So it is clear that the role of professional therapists is primarily with disabled children and recently disabled adults and their families. But the point to be made is that their role is to minimise impairment and to maximise adaptation to a new lifestyle, and not to treat disabled people as though they must be cared for for the rest of their lives. Their task is to remove barriers at the individual level.

Many programmes in disability in the South are aimed at children, and it is obvious that resources of time, money, and expertise should be focused on them. But children grow up, and unless these programmes are set within a full understanding of the social context of disability, the negative cycle of patronising attitudes and a feeling of disempowerment among disabled people will be perpetuated, however good the rehabilitation is technically.

Finally, there are increasing numbers of cases where disabled people and professionals work closely together, several illustrated in the case studies in Part Three of this book (for example Zanzibar and Zimbabwe). Even though it is not a developing country, it is worth mentioning the example of New Zealand. In 1983 three organisations, Rehabilitation International (NZ) (a body mainly of professionals), the New Zealand Coordinating Council of the Disabled, and Disabled People's International (NZ) united to form the Disabled Persons' Assembly. At that time the Disabled Persons' Assembly 'was the only organisation in the world which had as members individual people with disabilities and their service-providing organisations working together as a partnership, but with constitutional power in the hands of the disabled individuals. The service providers are corporate members.'²¹

This chapter has argued that professionals and their organisations cannot dismiss organisations of disabled people as irrelevant. At the same time, the disability movement cannot dismiss the professionals as irrelevant. Changing attitudes comes through co-operation, and takes time.

Towards social action

*'An organisation of disabled people cannot simply talk about the problems.
It has to do something about them as well.'*

(Jabulani Ncube)

Three approaches to rehabilitation¹

In a recent survey, disabled people in Uganda were asked to list their needs in order of priority. At the top of their list came income, then housing, then transport, then sex. Rehabilitation came a bad fifth.² Yet the literature on disability in developing countries is predominantly about rehabilitation.³ The normal reflex when speaking or writing about disability is to discuss rehabilitation. This accounts in large measure for the irritation that disabled people feel towards the whole rehabilitation business, and for their perceived hostility towards the professionals: the plain fact of the matter is that the constant emphasis on rehabilitation perpetuates the idea that disabled people must be normalised, taken care of, treated as perpetual patients.

It should by now be obvious that this book is not primarily about rehabilitation, but about attitudes and approaches. However, it is important to take a hard look at rehabilitation, because it is precisely here that many of the negative attitudes originate and are perpetuated. In looking at rehabilitation, we have the following basic questions in mind:

- What attitudes and approaches are needed to make rehabilitation a developmental experience? In other words, how can rehabilitation enhance rather than diminish the personal growth and dignity of the disabled person?

- How far does rehabilitation advance integration and participation?
- Is rehabilitation seen as an end in itself, or as a resource for disabled people to use for their own development?

For the sake of simplicity and clarity we can fit present-day rehabilitation services roughly into three types: institutions, Community-Based Rehabilitation (CBR), and an approach using neighbourhood centres. These three do not stand in conflict with each other, but each may be more or less developmental, depending on how close it comes to answering the basic questions listed above. CBR is not necessarily more developmental than confining disabled people in an institution: it depends on the attitudes and approaches of the people involved.

The institutional mentality

Let's begin with institutions. This section will not be a tirade against institutions and all who run them, but an examination of where they fail to be developmental, and the valuable role they can play if they are run on developmental lines. We are not talking about buildings, but about attitudes.

The charitable, medical, and individual response to disability has tended to be the establishment of institutions. But it has been clear for a long time that classic, isolated institutions are both extremely expensive and an ineffective way of supplying the needs of disabled people. Not only do they cater for a minute number, but those who are in them often find it difficult or impossible to live outside them, cut off for many years from their own contexts. **Amer Mukaram**, head of the Youth Association of the Blind in Lebanon, was blinded in a shooting accident at the age of seven and spent nearly all of his school years in a residential institution for blind children:

I come from a mountain village, and from the time I became blind I was cut off completely from my home environment. My relatives considered that I was ill. The school for the blind that I attended was a welfare school. There was no contact with family or friends at home. All the contacts with people on the outside were very unbalanced. Sighted people would come to the school, but out of pity. It was impossible to form normal relationships with them: they were just doing us a service. They regarded us as poor people who needed our help. It took me years after I left to learn how to relate to people normally.



A long-term resident of Abu Samra Institution, Tripoli, Lebanon. It is not buildings, but attitudes, which create institutions.

However, despite the obvious drawbacks of institutions, there is a feeling among some government planners, non-governmental agencies, and especially private philanthropists in many developing countries that anything less than expensive institutions 'on the Western model' is something of an insult.⁴ The argument that 'disabled people deserve the best we can give them', when used in this context, is beguiling, drawing as it does on feelings of guilt. Institutions are also very visible and are an obvious way of expressing personal generosity and charity in cultures where such acts enhance esteem within the community, not to mention religious merit. They can also be an effective way to build a personal empire.

Institutions may not be a solution if you are starting from scratch, but they are a feature of the landscape and are likely to remain so. An institution-less revolution is not very likely. That being so, rather than damn them it is more constructive to see how they can be incorporated into rehabilitation planning. Large institutions on the traditional model isolate, segregate, and address only a fraction of the need. But they need not necessarily remain so: they can become a reference point for community action, or resource centres with a much wider impact. For example, the Divine Light Trust for the Blind at Whitefield near Bangalore in south India was set up in the 1950s as a school for blind children. Its director, Father Cutinha, explains what happened:

Take our institution here. It started as a school. But after about 35 years of running it as a school, it came as a severe trauma to me to discover that only about 5 per cent of blind children are in blind schools. I just could not believe it. After 40 years of national 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.

So we don't run it as a school any more. We run it as a resource centre for training teachers in ordinary schools in how to integrate blind pupils into their classes. Now, with the same budget and the same number of staff, we reach out to practically the whole of India. We motivate them to start services, and they come here for training. So we have made our point and proved ourselves by de-institutionalising. We are far more productive now.

But the sad thing is that I have made this point in umpteen workshops, but no other institutions have followed suit. The reason is that when such workshops are run, hardly anybody from the management side comes. It is staff who come, but the management does not come, and so the message never gets through to the decision makers of these institutions.

Existing institutions can become valuable resources to large numbers of people, both disabled and non-disabled, if they can make the imaginative leap that was made by the school near Bangalore. Scrapping institutions is not likely to happen, because of the personal investment that they often represent; but they have buildings, facilities, equipment, and skills that could be resources of immense value to their own wider communities. The main difficulty, as Father Cutinha explains, is getting that message to the decision makers behind most institutions, who tend not to read books on disability and development. However, it is important to believe that change can happen: in Chapter 12 we shall see an interesting and encouraging example of social action to change an institution in Lebanon.

Community-Based Rehabilitation (CBR)

It was a serious attempt to de-institutionalise, de-mystify, and de-professionalise rehabilitation that led to the formulation of the CBR concept in 1979 by the World Health Organisation (WHO).⁵ But unfortunately this term has been probably more misunderstood and

misapplied than any other concept in disability. It has been widely discussed in books, articles, and conferences since its introduction (there are several good summaries and critical analyses listed in the resources section at the end of this book), but confusion prevails.

'CBR promotes awareness and responsibility for rehabilitation in the community. The disabled person, the family and community members are called upon to take an active part in the process of rehabilitation.'⁶ A WHO manual, *Training Disabled People in the Community*,⁷ sets out how this can be done. A local supervisor is recruited from the community and trained; the supervisor then trains the family of the disabled person in basic rehabilitation supported by 'the community'.

CBR is thus based on two fundamental assumptions: that the greatest resource for helping a disabled person is his or her own family, and that the community around that family can be mobilised in support. These are obviously good ideas in themselves, but like all assumptions they need to be examined. Let us take the role of the family first. There can be no question that the family is the main building block of any developmental process; it must be the centre of a child's experience and the structure through which most learning takes place. This is self-evident. But there are a number of problems attached to making the family the prime focus of rehabilitation; they do not negate its role, but they must certainly be borne in mind.

In the first place the family has always been, in the absence of any other services, the main source of learning, support, and help for the disabled child: there is nothing new in that. But there may well be factors (either practical or attitudinal) which prevent the family from helping the child. On the practical level the family, if it is very poor, may be so hard-pressed to survive that its members simply do not have time to devote to the rehabilitation of a child. This does not imply a lack of caring, but is simply an illustration of the fact that absolute poverty concentrates the mind on the absolute essentials. As soon as services become available, parents will use them for their children, but they may not have the energy or time to do systematic rehabilitation themselves.

On the attitudinal level, regardless of whether the family is poor or not, the role of a parent is different from that of therapist or teacher. Every parent knows this. The relationship between parent and child carries a set of emotions that do not exist between the child and a therapist external to the family. In particular a disabled

child may produce an undercurrent of guilt in the mother which results in coddling rather than a robust encouragement to reach for independence, or a failure to appreciate what the child is capable of. Over-protection is more common than neglect as a reason for under-development in a disabled child; but whether it is over-protection or neglect, the fundamental problem for the child is the lack of challenge and stimulation.

It also has to be recognised that looking after a disabled child or adult can be very wearing. Parents and family need regular breaks. Planning any rehabilitation programme needs to consider this factor very seriously. Parents can certainly support each other, and one of the strongest arguments for neighbourhood centres (as opposed to institutions) is that they give the parents a break and also a chance to meet each other and share their mutual problems. But even without the facility of a centre, families can be encouraged to pair up so that a disabled member spends time on a regular basis with a support family, who may or may not have a disabled member of their own.⁸

So the point about families and community-based (or rather home-based) rehabilitation is that without adequate support, disabled people may be little better off than if they are parked in institutions.

The second major assumption behind CBR relates to community action. It is very difficult to impose a community approach from the top, by government decree or a decision made by development planners. Community action means different things in different contexts. The difficulty with the classic CBR approach is that it assumes a rather bland view of community action in which the entire community — family, neighbours, health service, social workers, local authorities, employers, carpenters, etc. — all play their part in recognising the needs of disabled people and fulfilling the three major objectives set out by the World Programme of Action on Disability: *prevention, rehabilitation, and integration*.

The reality is seldom so simple. The country case studies in Part Three of this book illustrate how differing contexts require very different approaches. However, one of the main points behind those case studies is to show that, whatever the circumstances, community action of some kind is possible when people at the community level see the point of it. The key point for development workers is to discover how to tap into existing community patterns and interest, rather than simply 'set up a project'.

Closely connected with the question of community action is the

Photo: Chris Johnson/Oxfam



A training course in rehabilitation work for village community workers, Kunaka Hospital, Seke Communal Lands, Zimbabwe

role of the CBR worker; this needs much thought. One of the main misconceptions about CBR as practised in many countries is that it is seen as another way of passing the buck of 'dealing with disability' to 'experts' who are designated for that task; the CBR worker goes round the houses 'doing rehabilitation'. It becomes a modified version of 'out of sight, out of mind', which defeats the whole object, especially if all the rehabilitation is done in people's homes, which effectively removes disability from the public domain.

There is a need for specialist CBR workers, but to do the job properly requires a high level of social and diplomatic skills: the prime task of a CBR worker is to 'skill' other people, which means the disabled person, the family, and other members of the community. The CBR worker cannot be the main source of learning and therapy for the disabled child or adult: the whole point is to enable the family to be that. So he or she needs to be a rehabilitation specialist, have a good understanding of individual and social psychology, and be a good development worker. He or she must be able to see beyond the physical needs of the disabled person and see when and how to involve and inspire other members of the community, perceive where useful connections can be made, gain the confidence of decision makers, and so on. It requires a sensitivity

and perspective based not on 'coming in as the rescuer', but on enabling and facilitating other people and fostering a climate of mutual trust and cooperation. This is no small task, and it is rare to find a sufficient number of people with these qualities who are not snapped up by better-paid jobs.

It has often been found that disabled people themselves do an outstanding job as CBR workers, because they have a perspective not shared by non-disabled people. This has been well-documented, for example by David Werner in the Projimo Project in Mexico.⁹

When the difficulties of implementing CBR in its 'pure' form as proposed by WHO are considered, it is hardly surprising that there are very few successful examples around, and that there is much literature which is critical of the concept as unrealistic.¹⁰ On the other hand, the term 'CBR' has become part of the jargon of development, three magic letters that are known to trigger the right response in the minds of funding agencies. 'CBR' has tended to become synonymous with 'development work in disability'. Even institutions themselves will say they are 'doing CBR' if they start an outreach programme. All this muddies the waters of understanding.

It is certainly not my intention here to be unduly negative about CBR as a concept. What is being challenged is an uncritical or muddled application of it as a panacea or as a total solution. The aim of any disability programme must be to fulfil the three objectives defined by the World Programme of Action, namely prevention, rehabilitation, and integration. CBR is often touted as the only way of 'dealing with' disability, but one of its dangers is that it can easily become focused only on physical rehabilitation of children at home, and nothing else happens. There has to be a co-ordinated way of dealing with the other important aspects of disability: prevention, equal opportunities, the supply of aids and appliances, access, integration in schools, and general awareness-raising.

Neighbourhood centres and local disability committees

Both institutions and CBR can play an important role in approaches to disability if they are developmentally managed, and in particular if they involve disabled people fully in decision-making and implementation. A third model that has the potential for a more comprehensive approach within small and clearly defined communities such as villages and long-term refugee camps is the local disability committee. Examples of these will be considered in detail in the case study of the Occupied Territories and Jordan in

Chapter 11, so I will merely sketch the outline here.

The basic concept starts with the formation of a committee whose members accept responsibility for disability within their own community. This committee can consist of disabled people, parents of disabled children, teachers, social workers, health workers, rehabilitation professionals, and anybody else in the community interested in the issue. They then decide what to do about disability in their own community. The first step might be to do a survey to see how many disabled people there are, what different disabilities they have, what age spread there is, what the likely causes are, and what services are needed. Some workers are sceptical of surveys, with good reason, but in my experience they can be a vital process which will raise both awareness and expectations; they can also be an important way of bringing the community in general into the planning process. Those conducting the survey should emphasise that any services must be managed by, and be within the capability of, the community, and they should also stress that some enormous institutional project is not about to materialise.

The committee can then develop a strategy which includes prevention, awareness raising, equal opportunities, integration, rehabilitation, and service provision. The strategy they adopt will depend on the findings of the survey, existing services, availability of funding, and opportunities for training. They may decide to set up a neighbourhood centre for children who cannot be integrated into normal schools. Neighbourhood centres, sometimes also called community rehabilitation centres, are small, low-cost centres where children (and parents) can attend to socialise and take part in a programme geared to their needs. The committee will also need to establish links with sources of appliances and referral centres, find ways of training staff for their own centre, raise money, and build links with other committees in neighbouring communities. If a CBR programme already exists, it can be integrated into their strategy. Developing links with institutions can only be a good thing, since at worst it may lead to nothing, but at best it may open the institution up to new ways of viewing the world and the wider use of valuable facilities.

The examples in Chapter 11 show how such committees can work in practice. Where they work well, the results are impressive. But there is no such thing as a complete solution: 'There is no single pattern of service delivery that can fit all contexts. Communities differ in many respects, administrative structure, legislative

provisions, population and population distribution, economic and cultural conditions, manpower resources. These variations will lead to different models of service delivery.¹¹ The crucial point about service delivery is that, whatever form it takes, unless disabled people themselves play a key role in its design and delivery, working together with able-bodied people, then it will not empower disabled people and will not achieve the three goals of prevention, integration, and rehabilitation.

Before considering how disabled people can be empowered in this way, we will need to consider the role of the State in all this.

The role of the State

'Private voluntary action is the distinguishing mark of a free society.' (William Beveridge¹²)

There is a tension in all countries between the role and obligation of the State and private voluntary action. Should the State act as the big daddy (or mummy) which takes care of all its citizens, or should it leave this task to private voluntary agencies? Are the causes of destitution to be found in the structure of society or in individual family lives? Who is responsible for shaping the society in which we live? These are very big questions, but they have particular relevance to the situation of disabled people, or indeed of any group who feels itself to be oppressed. Although this book is about disability and development in developing countries, the baseline principles underlying the discussion hold good everywhere. There are some useful lessons to be learned from the United Kingdom.

In the UK the foundations of the Welfare State were laid during Victorian times. The Victorians identified 'the poor' as a group, but saw them largely as a collection of destitute individuals; and so they plunged with great energy into philanthropy, setting up institutions and dishing out soup and shoes to pinched-faced people in the dark, satanic streets of industrial towns. But 'when the focus shifted from *the poor* and what could be done to relieve their distress, to *poverty* and what could be done to abolish it, then it became inevitable that the state should intervene more decisively and that the scope of private charity should be correspondingly altered'.¹³

'The poor' are the objects of charity; 'poverty' is the domain of politics. By this analysis private voluntary organisations in Britain deal in 'charity' and the State deals in 'politics'. In Britain this division is not only recognised; it is protected by law: it is illegal for

private charities to involve themselves directly in 'politics' — that is, they can deal with people in need, but may not seek to change government policy as it affects such people. To people outside the UK this distinction may seem illogical and bizarre, but it is broadly accepted by the British population, for philanthropy did not end with the establishment of the Welfare State in 1948: there are today over 180,000 charities registered in Britain, increasing by several thousand each year.¹⁴ We give our pounds and pennies to charities like Dr Barnado's for the individual child, and give our vote to whichever political party we think will deal with the problem at large, thereby affirming our belief that both politics and charity have a role to play.

But for disabled people there is a crucial issue at stake. We are back to the question of an individual or social problem, to private concerns and public issues, to individual need versus universal right. Are disabled people perceived by the government as the responsibility of the charities or of the State? Are they simply individuals with special needs, or is disability seen as an issue of fundamental rights? For **Joshua Malinga**, Secretary General of the Southern Africa Federation of Disabled Persons, there can be no question:

If the government passes disability completely to charity, it is avoiding its responsibilities. It is not enough to do a little CBR and provide drugs. I am a city councillor here in Bulawayo. Every year we sit down and say, What can we contribute to SAFOD, to NCDPZ, to Jairos Jiri? \$400 to SAFOD, \$400 to NCDPZ ... So what the council is doing is not accepting its responsibility to provide for disabled people in the mainstream. If you give \$400 to NCDPZ and divide that by the number of people NCDPZ is working with, then you are contributing about one cent or half a cent per capita to the disabled population.

Amer Mukaram, a founder member of the Youth Association of the Blind in Lebanon, believes that the crucial role of the government is to create the legal framework within which disabled people can claim their rights as citizens, like everyone else:

The practical way we want to achieve integration is to put pressure on the government to bring out a law which makes it possible to integrate. We must go beyond having relations with sighted people in which the sighted person is just a volunteer. Why not a friend? Just like ordinary people. The State has the responsibility to create the circumstances through which that can happen.

And Venkatesh in India:

The State should look after disabled people as it looks after any other of its citizens. In an ideal world it should look after their special needs as a matter of routine. That's my utopia. No fuss. Routine.

In order to create this routine, he advocates removing responsibility for disability from the Ministry of Social Welfare altogether:

I would influence the government to have a unit for disability in every one of its ministries, be it Integrated Rural Development, or Finance, or Commerce and Industries. That's what I would be aiming for. So that means that at the policy level you are integrating work with disabled people. Education, health, employment, housing, whatever. Which means that at the policy level we are not marginalised. So if that takes place, I think that's the beginning of integration at the national level.

Livion Nyathi, formerly of the National Council of Disabled People of Zimbabwe (NCDPZ), clarifies what he believes the government's role to be:

The role of the government is of paramount importance in co-ordinating, funding, researching and stimulating agencies and its own departments in the establishment of rehabilitation services.¹⁵

But in stressing that disability is an issue which demands basic rights recognised by the State, we should in no way be dismissive of private voluntary action. There is much wisdom in the quotation from William Beveridge that heads this section: private voluntary action is the hallmark of a free society. Where the State provides all, the human spirit itself seems to wither and die. Not only that, but without a flourishing private sector there is no mechanism for making the State accountable. Despite what has been said in criticism of 'charity' as a non-developmental concept, the private voluntary sector does represent the conscience of a society. The role of the government is to create the environment where private voluntary action can flourish, strongly supported by the State. Support does not imply control: private voluntary action requires State backing in both cash and legislation, but not control.

The way of social action

'Equality for oppressed minorities is never voluntarily given by entrenched authority.' (Justin Dart)¹⁶

There is probably no government in the world that has given rights to disabled people voluntarily; where it has happened, it has happened through pressure from disabled people working as a movement. The task is clear, but immense. Social action on disability is fraught with the same problems and pitfalls as social action on any other issue. The problems can be summed up in a few basic questions: to what extent does confrontation encourage change, and to what extent does it hinder it? Have the very militant sections of the women's movement, for example, pushed their cause forward or driven people (more moderate women and men) away? Does militancy, in other words, work, or does it alienate those it is trying to convert? Does social action have to be militant? How do you work for radical social and political change without being dismissed as extreme and therefore losing your audience before you have started? On the other hand, anger can be an enormous stimulus to action: when the pioneering nineteenth-century English nurse Florence Nightingale was asked what drove her, she replied, 'Rage'.

Does militancy work?

Among those interviewed for this book some were very militant, while others believed that militancy does not work. There are obviously times when anger and dramatic action are fully appropriate and justified, and other times when it is inappropriate. The case-study material supplies illustrations of effective militancy, for example in Lebanon (see Chapter 12).

Samir Ghosh, whom we met in Chapter 1, explains the dilemma in these terms:

I have always believed that the major effort should go into building a relationship with society, so that people understand that it's of mutual benefit to society as well as to the individual. It is very important for society to understand the benefit.

I am not of the attitude that we have got to snatch something. Because I think that's where there is a kind of indifference now. Rather than that, I would much rather bring the cause closer to society. I know it's a long process, but we've got to work in this area, where the real understanding is of mutual benefit; otherwise no matter how much we keep harping on about it, society will continue to use benevolence when dealing with disabled people and considering it a charitable act to rehabilitate a handicapped person.

I'll give you an example. When I walk on the streets, people look at me

It's something I can't avoid. I'm different. But whenever I'm asked a question about my disability, I always reply nicely and positively. The same person never asks me a second time. So I have at least educated one person. And it multiplies. For example, the manager of the Taj Mahal Hotel where I am staying came and asked me about my requirements, and I told him everything about me. Then I found that it was conveyed to the room boys and everybody. So it's automatically a multiple educating process. But if I was arrogant or embarrassed and replied accordingly, that would be counter-productive.

For Samir, strident militancy is counter-productive. The key lies in the spirit with which we approach the matter of changing attitudes. What Samir is saying is that people do not like being 'should upon'. Arrogance or self-righteousness are not good starting points for social action. If we want peace, then the way is peace, not hostility.

The second point Samir is making concerns mutual benefit. Just as global consciousness is changing on environmental issues because people recognise the interdependence of themselves and the planet, so real change in attitudes towards disability will come only when non-disabled people recognise what disabled people have to offer.

We are led back to self-esteem again. 'The basic social institution is the individual human heart. It is the source of the energy from which all social action derives its power and its purpose.'¹⁷ The spirit with which social action is undertaken will determine its outcome, so before we start, we need to know who we are. If we are at war with ourselves and with the world, it is unlikely that we will succeed in building bridges of confidence with people we wish to change. 'Our power will come from who we all are and know ourselves to be. It will be communicated in the quality of our presence, not just the substance of our message.'¹⁸

Jabulani Ncube was director of the National Council of Disabled People of Zimbabwe for some years in the mid-1980s. It is an organisation that has established a reputation for being militant. In his opinion:

There is a valid role for militancy. But a militancy that is not supported by concrete actions, by which disabled people have an opportunity to demonstrate a more serious commitment, runs the risk of being an empty type of militancy. What is important is that disabled people have not had an opportunity ever to plainly express their views, their own position. The vehicle of the organisation is the platform that now presents itself for them to stand up and present their position

quite unequivocally. In southern Africa and elsewhere, I think disabled people have begun to do that.

The noise that disabled people are making should be a constructive kind of noise. Not a noise of simply beating drums, attracting attention but being unable to move the issues forward. Disabled people do have to take the responsibility that they can do something. More respect will accrue to disabled people and their organisations if they can be seen to dedicate themselves seriously to action and hard work.

So while it is the easiest of things to stand up and blame all the problems that disabled people are facing on the government, on the lack of coherent policy, on able-bodied people not understanding at all, on the oppressors — we can call them by many names — I think the most striking manner in which one can impress an oppressor, if that is possible, is for the oppressor to be able to see what you can do. And I think they are likely to stop and say, 'Ah! Is that what they are saying?'

These are obviously not easy things, but I think it is an important part of the militancy for disabled people to retire back to their chambers and seek to define ways in which they want to move forwards and provide concrete examples of the improvements they wish to see in society in general. And then the government and other agencies working in development could be held responsible for implementation on a wide scale.

An organisation of disabled people cannot simply talk about the problems. It has to do something about them as well.

It is the combination of practical action and advocacy that forms the heart of any social action programme: there must be both to move the issue forward. The words must be matched by the action. Justin Dart, Chair of the President's Committee on Employment of People with Disabilities in the USA, has some very direct and powerful things to say on social action:

Human society is not a magical source of truth and solutions. Society and its governments are simply the sum total of what individual humans think and do every day. The illusion, the big lie, that paternalistic government can give quality of life, has resulted in a cancerous dependency, which has debilitated the people it promised to empower. We, as individuals, are the government. We are society. We, as individuals, as a movement, must empower ourselves, our government and our society, or empowerment will not occur. This is not a philosophy. It is a fact.¹⁹



A meeting of a village disability group in Tamil Nadu, India. Such groups have achieved much in practical action for basic rights.

So we return to our starting point: if there is to be change, it has to start with us, with those who want change, disabled people and their allies. How disabled people see themselves is the starting point. Self-esteem means feeling good about yourself and being sure of your own value as a human being. Feeling good about yourself does not mean accepting the institutionalised injustice meted out by society: it gives you the power to begin changing it. In Part Three of this book we look at a few countries where disabled people and their allies are attempting to do just that.

Language and numbers

This chapter forms a kind of appendix to Part Two. The book would not be complete without considering the important matters of statistics and language in relation to disability, but I have placed them in a separate chapter rather than incorporate them into the arguments of other chapters.

Language: examine the label

Our thoughts and attitudes are influenced by the language we use; we tend to slot into language patterns dictated by current usage and prevalent attitudes. For example, 'Poor Leila, who has a secretarial job, is suffering from multiple sclerosis and has been confined to a wheelchair for years.' Or 'John is a stroke victim who has been afflicted with hemiplegia and is restricted to special equipment to feed himself.'

Labels disable because they focus on the person not as a person but as a case or an object. Words like 'poor', 'victim', 'suffering', 'afflicted', 'confined', and 'restricted' all reinforce the notion of disabled people as sick and helpless. A wheelchair does not confine: it liberates the user to go out into the world to work, play, and be creative; it is a mobility aid, just as a car is for anyone who uses one. In most cases it may be inappropriate to mention that the person is disabled at all: is he or she identifiable only by the fact of being disabled? But if it is appropriate to mention it, each of these statements could be expressed positively, or at least neutrally, without any negative implication: 'Leila has a job as a secretary; she moves around in a wheelchair as a result of multiple sclerosis'; 'John had a stroke some years ago and is able to feed himself using special equipment'.

The use of language to refer to disability in English has changed over the past 40 years. Words like 'idiot', 'moron', 'imbecile', and 'lunatic' have mostly passed out of use, but are occasionally found in the press and popular writing. There are other old-fashioned words like 'invalid', 'deformed', 'cripple' which are still regrettably common.

Impairment, disability, and handicap

There is a great deal of confusion over the terms 'disabled', 'handicapped', and 'impaired'. But we need to be precise about these words in particular. Within the disabled community and among professionals dealing with disability the debate about their use continues. The World Health Organisation suggests three basic definitions:

Impairment: 'Any loss or abnormality of psychological, physiological, or anatomical structure or function', e.g. paraplegia.

Disability: 'Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being', e.g. inability to walk.

Handicap: 'A disadvantage for an individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual', e.g. lack of wheelchair access to public buildings and transport because no ramps are provided.

However, there are major problems with these three definitions. First, they are based on the medical model, to which the notion of 'normality' is central. Second, what is, in practice, the real difference here between an impairment and a disability? 'Loss of function' and 'lack of ability to perform' are pretty much the same thing.

The disability movement has generally rejected these definitions in favour of two basic concepts related to the social model of disability:

Impairment: 'The loss or abnormality plus the effect on function', e.g. paraplegia plus the inability to walk.

Disability/handicap: 'The disadvantage or restriction of activity caused by social factors which take little or no account of people who have impairments and thus exclude them from the mainstream of social activities.'

Most languages have only one word for the two English words 'disability' and 'handicap', so in the context of developing countries it does not make much sense to retain a distinction between them; 'impairment' and 'disability' cover the two essential concepts of *loss of function* and *being disabled by social attitudes*. That is the position taken in this book.

Language and identity

Debate also rages over the terms 'disabled people' or 'people with a disability'. The phrase 'people with a disability' has gained some currency, especially among professionals working in rehabilitation; but, apart from being rather clumsy, it is not strictly accurate according to the social model formula above, since it should be 'people with an impairment'. Most people in the disability movement would now favour 'disabled people', because that states clearly who they are. They argue that other minorities or oppressed groups do not use such circumlocutions; for example, we do not refer to black people as 'people who are black'. Black people are proud of being black, and disabled people have no reason whatever to be ashamed of being disabled: they want to claim their identity as disabled people.

What is not acceptable is to refer to 'the handicapped' or 'the disabled', because these expressions simply supply a label, without acknowledging that they refer to people. It is likewise not acceptable to refer to 'the blind' or 'the deaf'; to refer to an individual as 'a spastic', as though he or she is identifiable only by an impairment, is completely unacceptable, though regrettably still common.

Cultural differences in the use of language

In developing countries and in languages other than English there is probably not so much debate about language as there is in the industrialised North, and it is certainly not possible to be dogmatic about English language usage across the world. In India, for example, which uses English as a main form of communication, people with learning difficulties are called 'mentally retarded', even though that phrase has fallen out of use in Britain. In India the argument in its favour is that the phrase 'people with mental disabilities' could include people with mental illness, and it is important to distinguish the 'mentally ill' from the 'mentally retarded'. ('People with learning difficulties' does not seem to have caught on in India, probably because very few of these people are



Not 'the deaf one', but Hassan, a deaf child, playing in Jericho, West Bank.

lucky enough to be in 'learning situations', i.e. schools.)

But language is a cultural issue in relation to attitudes and self-perception. Naidu, a worker at the Association of the Physically Handicapped in Bangalore, southern India, who had polio as a child, remembers: 'In my village I was referred to as "the lame one", not by my own name.' The same is true in millions of small communities across the world: people are referred to by their physical characteristics, whether disabled or not: 'the dark one', 'the short one', 'the one with red hair', and so on. In Arabic, for example, there is a whole class of adjectival nouns used to describe physical characteristics. In the West we would contend that social integration requires calling people by their real names, not by their physical characteristics. But in many small communities in the South such labelling does not necessarily imply disrespect or discrimination (although it may do). Indeed, disabled people may well be much better integrated socially in such communities than they are in industrialised environments, despite such linguistic labelling.

Does language matter?

For some disabled people, their own personal development and sense of self-worth takes them beyond the hurt caused by labelling; for example, **Venkatesh** can say:

I prefer to be called 'blind' rather than 'a visually impaired person'. Whether you call me blind or visually impaired is not important. The most important thing is what I feel about myself. It's about self-esteem.

Venkatesh is perhaps unusual in having developed a sense of self-worth to this degree. Language remains an important issue for most disabled people, because it is so intimately linked with consciousness and attitudes. Drawing attention to language is an important way of exposing the unquestioned prejudices and assumptions upon which most people operate. Unexamined clichés govern the thoughts of the unthinking. Examining the clichés starts the process of constructive reflection on the issue. As Venkatesh himself says in the interview at the start of this book: 'People calling you not by your name but by your disability is just not on.'

Thomas Harris in *I'm OK, You're OK* sums up the importance of language in relationships:

I am a person. You are a person. Without you I am not a person, for only through you is language made possible, and only through language is thought made possible, and only through thought is humanness made possible. You have made me important. Therefore I am important and you are important. If I devalue you, I devalue myself.¹

Numbers: how many disabled people?

Nobody knows how many disabled people there are in the world. It is often claimed that disabled people constitute ten per cent of the world population, but this is a rough estimate which is not based on statistical evidence, and is not very helpful in practical terms.

Do the figures affect the fundamental argument for civil rights? No, they do not. No matter what the actual number of disabled people in the world, the case for civil rights is the same. Do the figures matter? Yes, they do, because looking at the statistics on disability reinforces the basic point that disability is defined more than anything else by two crucial factors: people's attitudes and the barriers erected by society.

The difficulty with the blanket figure of ten per cent is the

implication that ten per cent of any specific population is disabled; but this is rarely borne out in practice, and it leads to some ludicrous arguments. For example, some writers have assumed that in a world population of ten million refugees, one million are disabled; but a head count gives an actual figure of a few thousand. Although in extreme circumstances some will have died, this does not account for the enormous discrepancy. The problem lies in the assumption of ten per cent in the first place.

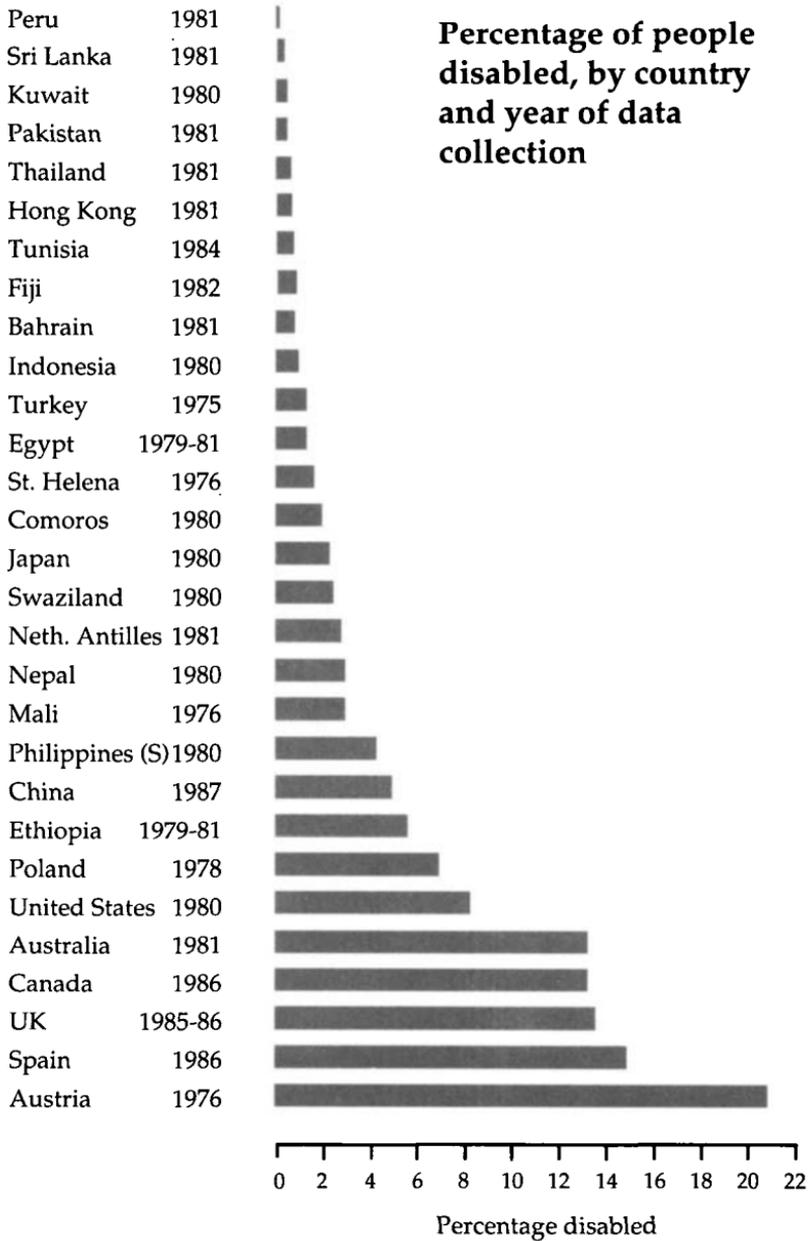
There is a very wide variation in the prevalence of disability within a country and between countries; it may be more or considerably less than ten per cent, depending on a variety of factors. As a general rule it seems that urban areas tend to have more than rural areas and, according to UN statistics, industrialised countries tend to have higher proportions than developing countries. Both these trends may come as a surprise, since they contradict received wisdom but, as we shall see, logic is on their side.

Global variations

Differences in definition used in surveys mean that all statistics on disability are inherently problematic. The United Nations Disability Statistics Compendium² shows Peru, Ethiopia, Egypt, Pakistan, and Sri Lanka as having a disability rate of less than one per cent, while Austria claims 21 per cent, and Australia, Canada, Britain and Spain apparently have 11 per cent and above. In the middle are countries like China, whose national survey in 1987 showed 4.9 per cent and Zimbabwe, where the National Disability Survey in 1981 indicated 3.4 per cent. (See the chart opposite.)

Where detailed surveys of specific communities have been done *within* developing countries, the results usually give figures much lower than expected. In rural areas especially, numbers are generally low: in a village of 2,000 people in India you would expect to find about 200 disabled people according to the ten per cent estimate, but in practice the number rarely exceeds a couple of dozen at the very most. In surveys conducted house-to-house in villages near Madras by PREPARE, a local NGO working in social action and community health, the figure was less than one per cent.³ In each of the surveys conducted in refugee camps in Jordan and the Occupied Territories before the establishment of neighbourhood disability centres, the figures were around two per cent.⁴

What do all these figures tell us? That Austria actually has over twenty times as many disabled people as Peru? Or that the Austrian



(Based on 'Statistics on Special Population Groups', Series Y, No. 4, *Disability Statistics Compendium*, United Nations, New York, 1990)

survey had a much wider definition and was more detailed? Or that disability is perceived quite differently in Austria and Peru? Even allowing for wide variations in definition, the figures flatly contradict the received wisdom that there is a higher proportion of disabled people in developing countries, and that impairment is a function of poverty. In the West the greater survival rate of disabled people and the demographic bias towards old age could mean that indeed industrialised countries have more. In very poor circumstances, such as Indian villages, the survival rate of children born with disabilities is extremely low. And the life expectancy of traumatically disabled adults in all parts of the developing world is dramatically lower than that of their Northern counterparts. For example, in South Africa vast differences in the standards of medical care for whites and blacks mean that a spinally injured white has a ten times greater chance of surviving until late middle age than his or her black compatriot.⁵

Urban and rural differences

Some figures show there to be an urban bias, and some show the reverse. My own observations while collecting material for this book, reinforced by a large number of specific studies,⁶ strongly support an urban bias. Reasons include the greater risk of injury in road and industrial accidents, the attraction of possible services and institutions, better medical care, the higher likelihood of finding sedentary jobs, and the possibility of begging. (In Indian cities children are sometimes maimed deliberately in order to make them more profitable beggars.) It would almost certainly be incorrect to assume that because 80 per cent of the population of a country live in the rural areas, 80 per cent of the disabled population are to be found there as well. However, even in rural areas there are wide variations: in some villages in Zaire more than 30 per cent of the population may be affected by river blindness, and in some African countries there is a high local incidence of disabling diseases like filariasis, which produces elephantiasis.

The effects of war

In a number of developing countries war accounts for significant numbers of disabled people. Cambodia has many amputees who have trodden on land mines, and in Angola a 'low-intensity conflict' (LIC) policy by South African-backed forces in the late 1980s deliberately set out to maim as many people as possible. David

Werner, who made a visit there in 1989, reports:

The large number of disabled people visible throughout Angola is part of the strategy of LIC. Leaving people seriously disabled puts a greater economic burden on families and on the nation than does killing people. It also takes a bigger toll psychologically: disabled people remain far more visible than the dead.⁷

However, we must beware of figures which are politically manipulated. In conflict situations casualty figures are often inflated, including disability figures.

Cultural differences in the perception of disability

It is the problem of definition which renders such highly generalised figures as ten per cent unhelpful. The definition of disability used by the Zimbabwe National Disability Survey of 1981 was:

A physical or mental condition which makes it difficult or impossible for the person concerned to adequately fulfil his or her normal role in society.⁸

This definition works well for the arguments in this book, but for a survey it is important to define which impairments are truly incapacitating and which are not. Are dyslexia and flat feet (both included in the definition used by the World Health Organisation) real disabilities in a Zimbabwean village? Almost certainly not, but total blindness or the loss of a lower limb would be. Are we talking about functional impairments or perceived disabilities? Why is it that in most societies spectacles do not carry a stigma, but a hearing aid does? How *do* you define disability for statistical purposes?

The statistics already quoted which show an urban bias and a heavy weighting towards developed countries cannot be dismissed as meaningless: they underline the fundamental point that disability is relative and depends for its definition on local attitudes and physical barriers, which change from one society to another. A mobility or visual impairment may be more of a disability in a Western urban environment than in a village in the South where there are no buildings with stairs, no pavements with kerbs, and no newspapers to read.

The problem of over-estimation

Realism is essential. There is as much danger in over-estimating the

numbers as in under-estimating them. If the figure of ten per cent is used blindly and all calculations are based on it without doing specific and detailed surveys, the size of the problem is likely to appear so daunting for hard-pressed governments and those planning services with slim resources that they may be reluctant even to embark on concerted action. Inflated estimates can lead to poor project planning and wasted resources, and also encourage the myth that disability is somehow competing with other fields of development for funding. In terms of political lobbying by the disability movement, there is more credibility to be gained by professionalism and accuracy than by assertions based on inaccurate estimates. I say this with the interests of the movement at heart; I believe its credibility can only be damaged by continuing to use the figure of ten per cent.

The ten per cent figure has in any case now been discounted by WHO itself. The author of the WHO Manual on Community-Based Rehabilitation, Dr Hillender, who was responsible for declaring ten per cent to be the world average, now favours a figure of about four per cent for developing countries and seven per cent for developed countries.

The main purpose of any survey should be to lay the foundations for service delivery. A therapist and child at a clinic in Glenview, Harare, Zimbabwe.



In terms of planning it is the need for services that ultimately matters, and the main purpose of any survey should be to lay the foundations for service delivery. However, there are considerable dangers attached to surveys. It scarcely needs pointing out that doing a survey with no follow-up or service delivery is a very cruel blow to those identified: a survey raises expectations of a measurable improvement in their lives, and should be done only as part of a general plan for service delivery.

What surveys and statistics do not show is the economic and human impact of, for example, a disabled child on a family. It inevitably falls to the mother to care for the child, which may have knock-on effects on income, the mother's health, and the health of other children. It is therefore specially important to ask women in any survey, and not rely only or mainly on answers from men.

