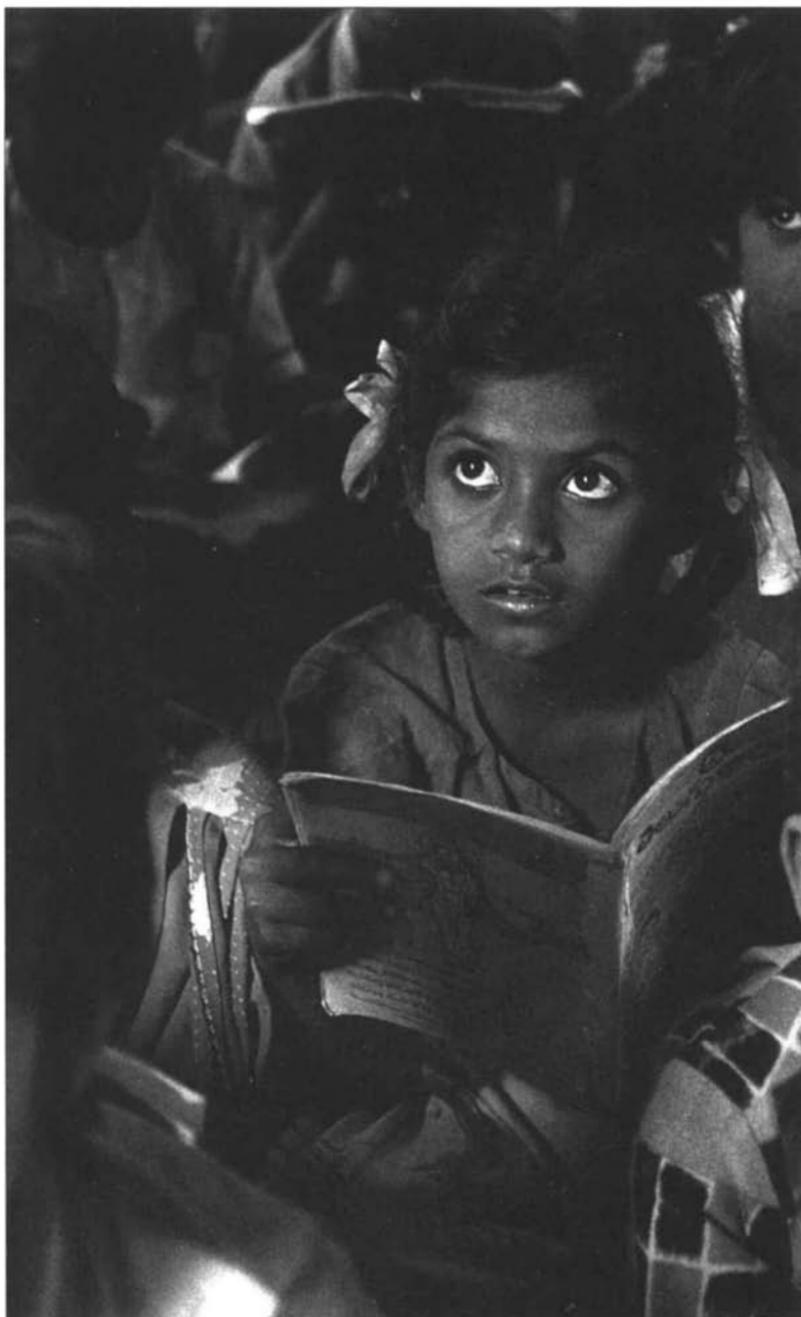


PART ONE

Introduction



A village school near Anantapur, Andhra Pradesh, India.

Why this book?

de-ve'lop: *v.t. to unfold more completely; to evolve the possibilities of; to make active (something latent); to advance; to further; to promote the growth of; to make more available or usable. v.i. to grow, evolve, expand, mature, ripen, to unfold gradually (as a flower from a bud).*¹

Charity or development?

Attitudes to development during the past forty years have, across the world, recognised that charity on its own is inadequate, and that the only meaningful development is when people plan and implement solutions to their own problems.

What creates change? Is it achieved by feeling pity towards people who are poor and oppressed — or by poor and oppressed people recognising their own strength to solve their own problems? Is it achieved by one lot of people, the 'haves', trying to meet the individual needs of another lot of people, the 'have nots' — or by people feeling their own power to meet their own needs?

We could, crudely, characterise these contrasting approaches as *charity* and *development*. Charity does nothing to challenge or change the status quo; indeed, it perpetuates it. Development is about people understanding the causes of their under-development, and with that understanding working to change their situation. In other words, development is ultimately about people having control over their own lives. Charity is about people remaining as victims, controlled by others.

Attitudes to development have indeed shifted in the past forty years, away from charity towards the empowerment of people. But

this shift has not, generally speaking, been apparent in work with disabled people. Programmes and projects in disability, especially in developing countries, are still in the main designed exclusively by able-bodied people, and tend to leave disabled people out of the decision-making process. The case for regarding disabled people as an integral part of the development process, capable of running their own lives and acting as full partners rather than passive recipients of rehabilitation, has hardly been made.

This book is an attempt to make that case. It is a personal examination of some of the social, political, and developmental aspects of disability, as they are encountered in a few widely differing developing countries.

Welfare or empowerment?

The situation of disabled people provides a microcosm of the whole development debate and process. Disabled people are oppressed and marginalised in every country of the world, in both North and South. They are oppressed by social attitudes which stem from fear and prejudice. By examining these prejudices and studying examples where they have been overcome, we gain an insight into the processes of liberation and empowerment that lie at the heart of any development effort.

The literature on disability is vast and growing. There are many excellent books on the medical aspects of rehabilitation in both the industrialised countries of the North and in developing countries. In the North there is also a growing literature on the politics of disability and empowerment of disabled people, written mainly by disabled people themselves, and already creating major changes in perception.² Outside the specialist field, popular books and films like *My Left Foot* by Christy Brown and *Children of a Lesser God* have made an undoubted impact on public awareness and attitudes in Britain. At the same time, stereotypes and negative images are still portrayed in films like *Hook*, and all countries still have a long way to go in overcoming institutionalised prejudice towards disabled people.

In developing countries the disability literature tends to focus on the medical and technical aspects of rehabilitation, especially nowadays Community Based Rehabilitation (CBR). But very little work has been done on the social and political aspects of disability in developing countries. The voice of disabled people themselves in the South has hardly been heard.

In many developing countries disability is often perceived by governments and aid agencies as a problem, but not as a priority. Income, access to land and/or jobs, basic health care, the infant mortality rate, and the provision of sanitation and clean water are all seen as greater and absolute priorities. These are the pressing problems, and disabled people can be attended to later. Among people working in development, a common reaction to my proposal to write this book was 'What has disability to do with development?' Even people who are 'progressive', 'gender-aware', and in all other respects 'developmentally minded' perceive disabled people as belonging to a category marked 'social welfare', which is the new term for 'charity'. The implication is that disabled people can be ignored altogether in the development debate.

So charity rules OK. Paradoxically, money is available from governments, aid agencies, and private donors for institutions and programmes in disability, usually prompted by the sense that 'We must do something for disabled people'. There is an enormous industry based on disability, in which charitable institutions vie with 'community-based programmes' for major funding; vested interests are well entrenched among rehabilitation professionals; UN agencies and NGOs debate disability at their conferences.

However, all this completely misses the point: most decision makers in development organisations are able-bodied and have never been exposed to the full potential of what disabled people can do for themselves. Existing models of project design, no matter how 'community oriented', tend to treat disabled people as recipients rather than participants in the decision-making process. In the conference rooms of Geneva and New York, disability programmes are discussed, planned, and funded with hardly a disabled person present. The disability movement and organisations of disabled people tend to be regarded askance by rehabilitation professionals, with the argument that if the aim is integration, there is no point in creating a separate disability movement. Among professional carers and the general public there is a dislike of militancy exhibited by disabled people — who, it is assumed, should keep quiet and accept their situation as unfortunate but unchangeable.

A different vision of disability

Most disabled people in developing countries, if they have been exposed to any services at all, have experienced only a medical or institutional model of rehabilitation, which treats them as passive.

The idea that they are capable of organising and running their own lives, including their own rehabilitation, has hardly been tested in most places. The result is that the individual medical model of rehabilitation, which treats disabled people as patients who need to be cured or cared for, whether in institutions or 'in the community', is perpetuated without serious questioning, even by disabled people, for want of a different vision.

But there is a different vision, in which disabled people themselves play a full part in the decision-making processes that shape their own lives. It is in every sense a liberation struggle, akin to the struggles of oppressed groups everywhere, in which some human beings are struggling to be taken seriously by other human beings and to overcome the imbalance of power that consigns them to the lowest ranks in a pecking order dictated by vested interests rather than values. This book is an exploration of that vision.

The individual medical model of rehabilitation creates dependency and patronising relationships; it is also inadequate to reach the millions of disabled people throughout the world, given the limited resources of developing countries. The evidence presented in this book demonstrates that a social model, in which disabled people play a full part in development decision-making, is not only a realistic and achievable goal, but offers perhaps the *only* viable way of extending opportunities for rehabilitation and decent lives to as many disabled people as possible.

Disabled people are engaged in a liberation struggle, but there is one crucial difference from other liberation struggles by oppressed groups. If we speak of the struggle by indigenous people to survive in the Brazilian rain forest (an extreme but topical example), we are speaking of a clearly defined group of people to which the vast majority of us do not, and never will, belong. The same is not true when we speak of disabled people. Disability is an issue that touches us all. It is not only, or even mainly, associated with poverty: disability can affect anybody of any background, in any country at any time. Per head of population, there is a greater proportion of disabled people in industrialised countries, where better health care means that disabled people live longer, than in poor countries, where survival rates are much lower. Many people in industrialised countries will experience disability in some form when they get old. So disability is an issue 'in here', not 'out there', whether we live in Birmingham or Bombay. It is 'all our' problem, not 'just their' problem.

How this book was written

Oxfam (UK and Ireland) generously released me from my normal post in its Middle East programme for seven months to undertake a study of disability in Zimbabwe, Zanzibar, India, Lebanon, Jordan, and the Occupied Territories, places where there are attempts to find a new vision based on development not charity. There are many other places where a new wind is blowing, and my choice of countries may appear somewhat random; but they all illustrate widely different political and cultural contexts for development, and between them represent a large part of the spectrum of diversity in approaches to development work.

The common starting point in each of these countries is a realisation that the medical model of disability, in which the disabled person is treated mainly as a patient or client with only medical or physical needs, is wholly inadequate. The evidence from these countries illustrates a recognition that, whatever form of service is applied — whether institution-based, community-based, or whatever — disabled people are human beings with all the economic, emotional, physical, intellectual, spiritual, social, and political needs that other people have. The main implication of this is that unless they are involved in the planning and implementation of services, these services will always be inadequate in extent and in philosophy, whatever form they take. A disability programme, no matter how 'community based', is not developmental unless disabled people play a leading part in its design and implementation.

The material for the book was gathered principally from conversations with disabled people in the developing countries named. The people interviewed included disabled people in villages, leaders of the disability movement in each country, and disabled people running their own organisations. Over 300 people in all were interviewed, with most of the conversations recorded on tape. Numerically people in villages were by far the largest group. There was a preponderance of men over women, a factor perhaps determined by my own sex, but also reflecting male dominance among disabled people too: men tended to come forward and women did not.

I greatly regret that I was not able to meet and interview more women: there are obviously clear parallels between disability issues and the issues surrounding the role of women generally. I recognise that the small number of women interviewees is a serious flaw in the

book. I also recognise that neither the women's movement nor the disability movement has adequately begun to address the double disadvantage that disabled women face: that of sexism and 'handicapism'. I have tried to illustrate this in the country case studies, and sincerely hope that this crucial issue will be addressed in greater depth by other writers with more direct experience than me. (Some material already published is listed in the Further Reading section at the end of this book.)

A personal statement

For me personally the discoveries recorded in this book have been a transforming experience. It has immeasurably strengthened my faith in the power of ordinary people, even in the most desperate circumstances, to effect real change in their own lives. It has led me in particular into a deeper understanding of the psychology of being disabled: the sense of loss, but the discovery of hidden strengths; the feeling of being rejected, but the ability to overcome rejection and be accepted as a full human being; above all it has shown me ways in which the demoralising patterns of negative attitudes and patronising relationships can be broken — by disabled people themselves. It has also been a discovery of the whole psychology of helping and being helped: in the final analysis we are all, whether disabled or not, both helpers and helped.

I began the project with some misgivings at not being disabled myself, aware that the most effective message will come from disabled people. But there are three things to be said about that.

First, the disability movement is not an exclusive club. Non-disabled people do have a role to play in helping to move the issues forward, as friends and allies. The disabled people interviewed for this book have given me nothing but encouragement. We are all part of a common humanity. All my contacts with disabled people have enriched my own life immeasurably: we can all contribute to each other's growth. But they are apprehensive about non-disabled people speaking on their behalf: that is indeed their main criticism of the professional carers and those with a stake in the rehabilitation industry who feel they have the final word on disability. The reader must judge whether I have fallen into this trap. I have tried to write as an able-bodied person with a deep interest in human development, for whom the situation of disabled people represents a microcosm of the whole human condition. A different kind of book would emerge from a disabled writer.

Second, the process of researching and writing the book has been an ever-deepening journey of discovery for me. My own attitudes as a non-disabled person have been transformed by what I have learnt. The change in my attitude is best summed up in the question, when I am with a disabled person: 'Am I the reason why this person feels disabled?' Everybody is affected by the attitudes of those they are relating to, and everybody knows what it feels like to be 'disabled' by another's manner, when we are treated with disrespect or in a patronising way. Conversely we also know what it feels like to be 'enabled' by another, when we feel that he or she respects us as an individual and relates to us as an equal. I hope that this book will help those who read it to be enablers rather than disablers. In this sense the book goes well beyond an examination of 'disability' and is really about how all of us, whether disabled or non-disabled, can live lives of greater value to each other.

Third, it is conventional to identify a segment of the human race as 'disabled'. But, as a visitor to a French naturist village recently observed, 'physical perfection is so rare as to be an oddity'.³ In other words, human beings are ranged along a continuum between 'disabled' and 'able-bodied'. Disability is relative to culture and circumstances. It is important to hold this paradox in tension: disabled people need liberation, but defining who is disabled is not an easy matter. We all have differing abilities.⁴

Values and interests

My own concern about disability results from a growing disillusionment with an approach to development based chiefly on material and economic factors. The division of the world into 'rich' and 'poor', or 'developed' and 'developing', is as problematic as dividing it into 'able-bodied' and 'disabled'. To determine a people's 'state of development' by income levels or gross national product alone is a one-dimensional, materialistic attitude that leaves out the whole range of social, cultural, and spiritual factors that give meaning to people's lives. It is obvious to me that those unencumbered with material possessions often have a deeper wisdom than those who live their lives in an unending pursuit of material gain. More wealth does not imply more wisdom. I believe that aid agencies, including Oxfam, carry a large responsibility for perpetuating (albeit unwittingly) the ridiculous notion that those in 'the South' are automatically 'worse off' in every way than those in 'the North'.

Of course I agree that poverty is a blight on the face of the planet, and that in the final analysis we are talking about the need for resources to be distributed fairly; but tackling poverty only through economic programmes has solved none of the massive problems with which we live. There is an increasing awareness among those involved in development activities that there are no easy solutions; the glib optimism of the 1960s and 1970s has given way to a more sombre realism. Neither the mega-programmes nor the micro-projects have managed to 'abolish poverty'. Poverty will never be 'abolished' by a system that is run only on materialistic principles; indeed, 'development' based on the notion of acquiring more material benefits will always enrich some and impoverish others. The myth of economic growth as the key to development needs to be challenged.

There are values and there are interests. Values are what we believe in — things like democracy and respect and empowerment. Interests are the actual forces, usually economic, that drive political activity. Governments on the whole behave according to what is in their economic interests, seldom according to values. Refusing to sign an environmental treaty protecting bio-diversity because it is bad for business is a glaring example of operating by material interests rather than universal human and planetary values.

Values define how we would like the world to be; interests dictate how it actually is. It is probably inevitable that interests will be the main engine of action in the world, and the economist Adam Smith believed that a 'hidden hand' ensures that self-interest will always serve the common good in the end. I'm not so sure. It is clear from the environmental debate that unless political action is based on the fundamental values of respect for life and a responsible husbanding of natural resources, the planet is doomed. In other words, unless our actions are actually based on the eternal values of respect for life and for each other, our long-term interests will not be served. So in the final analysis, values and interests do coincide; but this has not been grasped, on the whole, by those who determine the course of things.

The problem with a purely materialistic approach to development is that it is based on short-term and short-sighted interests, rather than the deep values which actually serve our ultimate interests. Disability leads one into different pathways, different mind-sets, a different way of looking at the world and what development means, because it does indeed challenge the

prevailing ethic of measuring 'success' by material achievement. There is something else, and it is more important:

*The earth does not argue,
Is not pathetic, has no arrangements,
Does not scream, haste, persuade,
 threaten, promise,
Makes no discriminations, has no
 conceivable failures,
Closes nothing, refuses nothing,
 shuts none out.*

(Walt Whitman: 'A song of the rolling earth')

What is our vision for the world and for the society in which we live? Is it one in which the fittest, the toughest, the most agile, the most aggressive, those with the strongest self-interest, thrive — and the rest merely survive? Where anybody who is 'different' is shunned, and where there is a worship of uniformity? Or is it a society in which diversity is welcomed and individuals are each valued for what they are? Do we want a world which makes discriminations, or do we want a world where none is shut out?

Development based only on material interests inevitably implies the success of the strong. Disabled people can show us a different way, and lead us into an approach to development based on the profound human value of respect for each individual life. The key words are *liberation* and *empowerment*, the liberation and empowerment of all human beings to fulfil their own potential. The liberation and empowerment of disabled people provides an insight into the liberation and empowerment of all oppressed people: the process is similar, but in the case of disabled people the focus is extra-sharp.

An early draft of this text triggered a comment by one reader that there are two books here wanting to get out: one on development and one on spiritual values, and I should make up my mind which the book is actually trying to deal with. My response is that I see no difference between true development and spiritual values; they are the same thing. 'The earth ... has no conceivable failures, closes nothing, refuses nothing, shuts none out.' That is the credo of this book.

It is a process book, not a handbook or a definitive analysis of a complex subject. It is a beginning, on which others can build.

Opinions, attitudes, and ideas among disabled people about themselves, about development, and about disability issues are just as diverse as those held by non-disabled people. Those interviewed for this book range from militant leaders of the disability movement to people who want nothing to do with the movement, and all shades between these two extremes. What unites them is the common desire to be accepted as fully paid-up members of the human race.

In October 1987 a large group of people in wheelchairs staged a peace march with other disabled people, to demonstrate against the war in Lebanon. They trundled through all the main cities on the coast, from Tripoli in the north to Tyre in the south. They had many critics, and many supporters. Some said they were mad, some said they were brave. By the time they reached Tyre, the march had become a cavalcade and the city dignitaries turned out with thousands of others to meet them. They had passed through numerous militia check posts along the way, and the armed men had nothing to say.

Who creates the vision for society? Do we leave it to the men of power and violence? For evil to triumph it is enough that good people do nothing. If we want a more humane society based on the values of respect and compassion for each other, then we have to create it. The people in wheelchairs who trundled from Tripoli to Tyre were setting out to do just that.

Setting out the issues: an interview with B. Venkatesh

'If people feel good about themselves, they can start to create change.'
(Venkatesh)

This book is intended primarily as a stimulus to thought and discussion. It is certainly not a prescription or a gospel. If you find yourself disagreeing strongly with a particular view, that is all to the good: only through critical discussion can we move away from slogans and the pernicious idea that there is one view that should prevail.

B. Venkatesh, or Venky as he is generally known, is director of Action on Disability and Development (ADD) India. He has been blind since his teens as a result of *retinitis pigmentosa*, a condition which accounts for about 2 per cent of blindness in the world today. In the interview that follows, Venky speaks about the central disability issues that will be discussed in this book.

I imagine that many able-bodied people and perhaps some disabled people reading this book will be rather similar to me when I started out on this project: aware that there is something drastically wrong with the way disabled people are regarded and treated, but not able to define precisely where the problems lie. In approaching Venky, I wanted views on the basic questions as he saw them. The answers he gave are not the only answers. They are his answers, which can be considered and agreed with or challenged. Complete answers or final solutions do not exist except as dogma; anyone who

claims to have the complete answer has probably not understood the question.

An interview with any one of the many disabled people met during the research for this book could have been used as the starting point; each would have had its strengths and weaknesses. The point is, we have to start somewhere. This is a process book which sets out to explore, not to define.

I asked Venky first about language (which will be discussed in detail in Chapter 7).

Venkatesh: I prefer to be called 'blind', rather than a 'visually impaired person'. 'Visually impaired person' is such a mouthful. 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. I don't get hurt by being called blind. It's a mechanism I've built within myself. It's a matter of survival, of self-defence. What you are called makes no difference, because your sense of self-worth rises above that.

Q: So does that mean that blindness is part of your identity which you feel quite happy with?

If I am what I am today, you know, deep inside, the way my mind works, it is because of my disability. Disability has enriched my life as a person.

Q: How has it enriched your life?

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. Anger is a very powerful emotion. But properly channelled and directed, anger is very positive, socially and to oneself.

Photo: ADD India



Venkatesh (Venky), Director of Action on Disability and Development (ADD) India.

Q: How have you yourself dealt with this question of other people's attitudes?

Like anyone else I have had to play many roles, as a child, a teenager, an adult, and so on. I have not been blind from birth. I could read and write until I was ten years old; I could play cricket and football; I could move about using vision until I was eighteen. My blindness came upon me gradually, so in the early years I had internalised what you may call 'normal behaviour'. In each of the roles that I have played and will play until I die, the issue for me is to be a good student, an effective manager, a good lover, and be good at having fun as well. I have continued to play the roles I played when I could see, which means simply being myself. I have not worked consciously at trying to get positive attitudes from people. I believe that a positive attitude in me will beget positive attitudes in them. I have always worked at being positive in anything I do, whether sighted or blind.

Of course I have met negative attitudes, especially from strangers when I travel, and I have to deal with them. But I have found that even in these situations, if I have a positive attitude, it gets a positive response from them.

. At one time I also had a kind of determination to beat people at their own game, to refuse to admit defeat, to show that I was as good as anybody else at anything I tried.

This was the trip I was on, and it was a mistake. It came from a sense of insecurity. I wanted to prove that being blind did not stop me from being as good as the next person. From there it was also natural to go for status: good money, a good job, and all that. But I realised I was losing touch with myself in trying to be that superman. I've been fortunate enough to be sensitive to that and come out of it. I've passed a stage where I don't have to do that, because I've got there. I mean not in a smug sense, but in the sense of being accepted for my work and what I am. And so I can be just myself now. But it took a long time.

Q: What convinced you that working in disability and not in the able-bodied corporate sector was the right way to go?

It was a matter of realising that the sector of disabled people needs people of competence and vision, and for some reason I believed that I have those qualities, rightly or wrongly. So I said, 'Let's work here.' And from there on I have grown far more than I ever grew in the corporate sector, chasing status and a 'good career'.

Q: Can you point to how your ideas have developed since starting to work in the disability sector?

I joined the Association of the Physically Handicapped, Bangalore, in 1980, and realised the need to reach more people than they were doing then. Services have to be provided to disabled people, but this country cannot afford a five-star rehabilitation service. Therefore the disability issue should be built into every sector, be it banking, or industry, or government. There should not be anything separate for disabled people. We must use existing structures.

Q: Do you see disability as fundamentally a social problem or as an individual problem?

It's both a social problem and an individual problem. Primarily it is a social problem, because what stops the individual disabled person from contributing is the attitude of non-disabled people towards him or her. It is attitudes which disable. These attitudes disable to the extent that disabled people do not have self-worth, they lack confidence, they believe that they are good for nothing, and therefore they become consumers rather than contributors to society. Once they become only consumers, then they are labelled as useless. So it is a vicious circle, but the starting point is attitudes by non-

disabled people, and that is where change has to begin.

Q: So you've got limited resources, limited time, limited people: where do you put your efforts?

My whole work now is about human resource development, developing people, enabling disabled people who are psychologically stunted and disempowered by social attitudes and religious prejudices. The primary aim of my work is to enable disabled people to feel good about themselves. How people feel about themselves has a direct impact on what they do and how they do it; unless they feel good about themselves, they won't be able to do very much. Furthermore, if people feel good about themselves, they can start to create change. So my effort is also in getting disabled people to understand the root cause of their own situation, and getting them to act to change the situation, if they want to. If they don't want to, no one can change it for them.

Q: What has influenced you most in that approach? It's quite revolutionary.

Work with disabled people is like a coin with two sides to it. One side is the special needs of disabled people; the other is attitudes. The services that exist today, as far as I know everywhere in the world, cater to special needs, but they do not address the whole issue of what it means to be a disabled person: what it means to be a disabled person in terms of psychology, and the social aspects of being disabled, the politics of disability. These two sides of the coin are crucial to the total development of the disabled person as a socially conscious creature. If there are not strong movements of disabled people in different parts of the world, it's because those disabled people who have had access to opportunity do not have this consciousness, and that is the tragedy of 150 years of rehabilitation work.

Q: You mean that the traditional rehabilitation approach has perpetuated a spirit of dependency?

Precisely. The rehabilitation process has reinforced the phenomenon of dependency, which we may call the disability mentality. It is evident even where disabled people have organised themselves in different parts of the world into self-advocacy groups. If they demand special concessions and privileges rather than equalisation, then they are perpetuating the disability mentality.

Q: You mean they are arguing for separate development?

Yes. It's so much in the consciousness of the elite in the disability movement, and it's the result of the whole process of rehabilitation. This mentality is evident everywhere. It all amounts to the same thing: an attitude of separateness and therefore dependency. It derives fundamentally from an attitude of religious charity: do good to a disabled person and you will find a place in heaven, as though disabled people are incapable of looking after themselves. These attitudes have always been there, and they are taking new forms today.

Nothing fundamentally has changed. If we want change, then disabled people have to become more aware. We are aiming at human dignity, not separate services.

Q: So if you were in the position of being a member of a national organisation of disabled people, what would be the things that you would be pressing for, say at the legislative level?

I would get disability work or disability policy taken out of Social Welfare. I would influence the government to have a unit for disability in every one of its ministries, be it integrated rural development, or women and children, or finance, or commerce and industries. That's what I would be aiming for. It 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.

Q: There are quite a lot of disabled people who will always be dependent. Quadraplegics, for example, who have to rely on other people to do things for them. Or another category would be children born with severe cerebral palsy who are in effect physically helpless. What would you do about people with that kind of disability?

If we are talking about education, they would come under the Ministry of Education; if health care, then under the Ministry of Health. It is not to say that disabled people do not have special needs. They do. But these special needs should be met by each ministry as appropriate, not by some separate ministry which is shoved away round the corner with a very small budget to work on.

Q: So what's the main disadvantage of having a specialist ministry?

The first thing is that by the very fact of having one, you are saying that we are marginalised. Second, the amount of money provided for such ministries is very small. Out of every rupee that we spend, 21 paise¹ are spent to service international loans, 19 paise are spent on defence, 2 paise on education, and 3 paise on health. So you can imagine what disability gets: it would be 0.000001 paise or something. So that shows that they want to marginalise it right from the word go. The resource allocation is so small that it's not worth it.

The third point is that by this process you would be trying to segregate disabled people in terms of institutions or whatever. Right from top to bottom what you see is segregation: that's what I'm dead against.

Q: Following this logic on, if one is looking for complete integration and not ghettoisation, how would you argue for or against movements of disabled people? I mean organisations which are exclusively composed of disabled people?

I have been talking about an ideal world, but it doesn't exist. Therefore there is a need for a movement, to press for this change: equalisation of opportunities.

Q: So you would argue for a movement of disabled people on the grounds that you have to be noticed in order to get equal opportunities?

You must demand equalisation. Unless you demand it, you're not going to get it. You've got to see the issues clearly: you can take advantage of disability: begging, or jumping the queue because you are disabled, are manifestations of that. But that means marginalisation. If that's what you want, then you don't want a movement. But in fact you probably still want a movement, because you still want to propagate that attitude of dependence — you know: 'poor me'.

Q: Obviously there is a vicious circle to be broken here. Many disabled people do not have access to education and therefore their levels of awareness are quite low, and therefore their political awareness is low. It would perhaps be unusual for them to have reached the level of understanding that you have. How do you aim to deal with that problem?

That question brings us straight to the work we are doing. I believe that disabled people who are not educated, who have no access to

literacy, are no less capable of being politically conscious about being disabled than those who have had access to literacy and education.

Q: You mean that levels of education do not necessarily correlate with awareness about disability?

Exactly. But the point is, disabled people do not have access to education, to childhood, to motherhood, property, housing, transportation, whatever. All these of course are basic rights of the human being. Given that they don't have these things, how can we get to a stage where they feel these are the things they want to work for? So in small groups of disabled people we sit with them and think through what it means to be a disabled person. 'I am a disabled person. I have brothers and sisters, and they are doing this, this and this. Why am I not doing these things? Whatever is going on in my village, I'm not party to it, I don't participate. Or it's a marginalised participation. Why? Is it because I am disabled? Or is it because someone else has decided how it shall be, because they have not seen anything different?' That's the reason: they have not seen anything different. They are seeing the same role-models for disabled people: you know, being a shepherd, or looking after children, or being a watchman.

Q: So creating different role-models is an important part of the task.

Absolutely right. Both disabled and non-disabled people need to see different role-models for disabled people in villages. They need to widen their horizons. There's a new project I've got funding for: 'Communications, Disability and Development'. It's to produce audio-visuals, street-theatre materials, and workshop material to promote this message of disability and attitude. It's about challenging disabled people who are stuck in this charity thing to decide whether they want change. Do they want to remain dependent? It's not just a question of asking for things from the government, for example, which is just a perpetuation of the dependency role. They have to believe that they can actually get from point A to point B if they want to. If that belief does not come from within themselves, if it's not internalised, I don't think anything can happen. This is a crucial first step with the disabled people with whom we are working.

We are working for fundamental change. We say to disabled people, 'It's for you to decide, whether you want fundamental change or not.' That is the issue. The questions of getting a government loan or a bus pass or a scholarship are all steps in this process of getting there, of building self-confidence, and finding strength in being disabled together.

Q: Would you support the idea of special facilities or special passes on the buses for disabled people?

I am not saying whether I support or don't support it. The point is that it is what disabled people out there want. I cannot change anything myself on my own. If they want radical change and real equalisation, they have to have belief in their own ability, and these interim measures help towards that. If you want to believe in collective action and see that it works, they have to have issues that they will succeed in. So if they want a shop, or a loan, or whatever, I think it's our job as activists to help them to attain those objectives. It's a question of how far our ambitions go. Do they stop at getting a bus pass or a loan, or does equalisation mean more than that to you? It's a process of growth, of development, of enabling people to be together and to find their strength.

We work across disabilities because we can then get disabled people to see that the problem they are dealing with is a common problem: it is a problem of attitude.

Q: What would you say is the role of the community in dealing with the question of service provision?

In an ideal world I would like service delivery to be done by organisations of disabled people. That is truly community-based. They would make the decisions about what services they want and who is going to be trained, and these people would come back and report to the disabled organisation. And the organisation would be responsible for getting the funds and administering the service.

Q: What would you see as the role of professionals in any kind of service delivery?

This professionalism is a non-issue in India. I don't want to make it an issue because some Western friends are trying to make it an issue. There are not nearly enough professionals anyway in India, so the question of their controlling disability on a large scale does not

arise. But having said that, I think that professionals, in an ideal world, should be managed by organisations of disabled people. Their job is to deal with the impairment only. But to get them into an activist role is a very dangerous thing, because they have so much power, from their expertise. Already they have enough power; we should not make them more powerful than they already are.

Q: And what would you define as the role of the State in service provision?

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.

Q: Why do you think the disability issue is so important in the development context?

First, disabled people are a substantial minority in the world, and most governments have not reached even 5 per cent of them. Second, disability dehumanises people. It dehumanises them because it drives them into total hibernation, like vegetables. That's not on. It's the worst form of human-rights violation. Many disabled people, especially mentally retarded and communication-impaired people, are left without any stimulation from the time they are infants. They have no childhood, boyhood, girlhood; they are not aware that they are 18 or 20 years old. They are in a state of permanent senility.

Q: So they are the opposite of socially conscious people.

Yes, they just live at the level of hunger and thirst. This is what social attitudes have done to them. That is why disability is a development issue: it dehumanises people. Those are extremes I have quoted; but the same phenomenon is manifested in all disabled people to some degree. But unless disabled people themselves want to change that dehumanising situation, then there isn't much hope that the situation will change.

Q: And you think it's only disabled people who can make the change?

Absolutely right. Because being disabled is so comfortable! We can

just sit on our backsides, and let it all happen. But if we do that, we gradually lose our sense of self-worth, and these expectations are not there. You just become resigned and do not demand any more. Disabled people have to get out of that shell. They have to be sensitised. People not calling you by your name, but by your disability, is just not on.

This interview reveals a mixture of idealism and realism. The key issues that Venky talks about are attitudes towards disability and the empowerment of disabled people. It is prejudice, fear, and negative attitudes which create the 'problem' of disability: if attitudes were not negative, there would not be a problem. So the task is to understand why these attitudes exist, and how they can be altered. Venky's view is that the process of change has to start with disabled people.

In the pages that follow, it is these two issues that form the constant theme of enquiry.

