

PART FOUR

Conclusions



In'am, coordinator of the Jarash community disability centre, Jordan, works with Murad, an autistic child.

Disability and liberation

*'The problem is not how to wipe out all differences,
but how to unite with all differences intact.'*
(Rabindranath Tagore)

For me the process of researching and writing this book has been one of the most significant experiences of my life. I feel I have travelled a long way into the realms of human development and have emerged with a whole new awareness of the resources of the human spirit. I have tried to be an objective, committed witness, intensely interested in the outcome but with no pre-conceptions, no axe to grind. As the Tao Te Ching says, 'The truth waits for eyes unclouded by longing'.

Whether I have succeeded is another matter. Did I really start with no pre-conceptions, no axe to grind? The most illuminating part of the process has been the discovery of my own prejudices. Even someone starting out with full sympathy and the intent to champion the cause of disability finds himself falling into the very traps that create the problem in the first place.

Levels of awareness

My own awareness has moved through three phases, three concentric circles of understanding.¹ The first and outer circle is the understanding that the 'problem' of disability is created by an able-bodied and disabling world that refuses to accept disabled people on their own terms. Prejudice and discrimination are the result.

The next circle is the understanding that change has to start with disabled people. That was the main message transmitted by nearly all the disabled people interviewed and is the central message of this book, suggested in the first half and illustrated by the case studies in the second. It neither negates nor eclipses the first circle of understanding, but rests on it.

The third circle has to do with the question of integration versus segregation, and the dynamics within the disability movement. This is the most difficult area in which to reach an understanding, because it touches very specifically on the question of power and control. Who controls? What is the relationship between the disability movement and the rest of the world? Cannot prejudice operate in both directions? The question of how power is handled once it is acquired is as important for the disability movement as for any other liberation movement.

There are other issues which, if you have stayed with the arguments and examples so far, you will be aware are not fully resolved. Is the social model of disability really sufficient to deal with the whole thing? Is it realistic, for example, to imagine the day when the birth of a disabled child will be greeted with the same joy as that of a non-disabled child? If you were told tomorrow that you had multiple sclerosis, what would your reaction be? It is prejudice that disables, but if prejudice is at base driven by fear, how do you get rid of fear, the fear of what might happen to you? Is this not a very individual matter, this fear? Is it not, when it comes to the crunch, a matter between you and your soul, and not between you and society? Pain and impairment exist, and that is not the fault of society but the condition of a particular body. It has to do with 'the unbearable heaviness of being', to adapt Milan Kundera's phrase. This perhaps is the fourth circle of awareness and understanding, not fully accessible to someone who is not disabled; each disabled individual will make his or her own response at this level, and it is here that individual personality plays the largest part.

There are parallels with other liberation movements, especially the women's movement, but disability is undoubtedly different in some respects. In the final analysis, what is the relationship between disability, liberation, and development?

Then there is the question of 'specialness'. I have said that disabled people do not want to be regarded as special, and yet at various points in the book I am saying they have something special to offer, something which non-disabled people do not have. I have

said they are not heroes or heroines — but clearly some of those quoted are exceptional people.

We have to hold all these things in tension. There is no neat resolution. In this final chapter I do not want to attempt a resolution, so much as draw things together into the different circles of understanding.

Basic needs and the quest for meaning

In the opening chapter I said that disability provides a way in to a deeper set of values. We need to return to that idea. Consider the matter of basic needs. Basic needs are lacks which need to be supplied, like food, shelter, and health. But there is a fundamental problem in seeing 'development' primarily as a process of meeting needs in this way. The problem lies in the fact that such needs are passive: if these needs are met, so this approach asserts, then 'development' has happened.²

But there are other needs which are just as basic: the need to be creative, to make choices, to exercise judgement, to love others, to have friendships, to contribute something of oneself to the world, to have social function and purpose. These are active needs; if they are not met, the result is the impoverishment of the human spirit, because without them life itself has no meaning. The most basic need of all is the need for meaning.

It is true that none of these active needs can be met unless life itself is not at risk of being extinguished by starvation; the quest for meaning requires, at minimum, knowing that there is a tomorrow. But to focus only on the bare maintenance of life as the object of development is to miss out completely on most of what human endeavour aspires to.

The quest for meaning is both a deeply spiritual and a profoundly political matter. The active needs listed above go unmet, are not even on the horizon, when people are no longer in control of their own lives in any meaningful sense, when the political, social, and economic forces that affect them are out of their reach and toss them about like chaff in the wind. The unequal distribution of resources, the growing gap between haves and have-nots, the insecurity of employment at many levels, corruption and incompetence in high places, major political decisions made only on economic grounds and out of narrow self-interest — these injustices wipe out the sense of meaning in poor people's lives and reduce life to a bare and grinding business of grim survival.



Our fulfilment as individuals is largely dependent on our relationships with those around us. Lola, a sighted friend, reads to Yahya, a blind student, in Tripoli, Lebanon.

It comes down ultimately to a question of rights and justice, but also of relationships. In theory rights and justice are reflected in laws; but the most enlightened laws are worthless unless in practice they are reflected in the way we relate to each other. Human life finds its meaning in relating. Our fulfilment as individuals is largely dependent on our relationships with those around us, set within an overall context which officially acknowledges our rights.

All this goes without saying. But it applies to everybody. We cannot use such arguments for some and not for others. We cannot say that such arguments do not apply to a portion of the population that is categorised as disabled. The liberation of disabled people is ultimately a question of justice and rights enshrined in law, made real by the empowering relationships that come from a genuine understanding by the rest of us.

An enquiry into disability and the social and political forces surrounding it brings us face to face with the purpose of survival, the way justice does or does not happen, and the central question of human relationships. The areas of life marked 'spiritual', 'developmental', and 'political' are concepts that amount, ultimately, to different facets of the same thing, which is the quest for meaning.

Identity, suffering, and 'privacy'

I think much of the apparent confusion and contradictions about disability issues can be resolved through the realisation that disability provides, for the disabled person, a certain experience or set of experiences that are not shared by other people. These experiences do set disabled people apart, but they also bind them, as it were, closer to life itself and its purpose. This needs some explanation.

Suffering brings insights. In my own life, a week spent in captivity in Lebanon is not something I would wish on anybody else, but I do not in any way regret the experience: it was of course brief in comparison with the experiences of other hostages, but it gave me insights into myself and the human condition which I could not possibly have gained in any other way. In that sense it was a 'given' experience, an experience which has formed part of the fabric of me as a person, an intensely personal experience. Most people can point to incidents of major trauma which are theirs alone. Everybody is shaped by the experiences that occur through their lives, and the apparently negative experiences often turn out to be the most formative. The same point has been made by a number of disabled people quoted in this book: they would not wish their disability on anyone else, they agree that it would be better for a child not to be born disabled, but their own disability is an essential part of their experience and their identity.

And yet saying that 'suffering brings insights' is problematic, because it reinforces the linkage between disability and illness. The only 'suffering', in the view of some, is knowing that people relate to you differently when you are disabled. In other words, if negative attitudes did not exist and if no barriers were placed in the way, permanent impairment would not be a problem. It is fear of the attitudes and the barriers that is the real fear, not fear of the impairment itself, which creates such negative feelings in the not-yet-disabled about becoming disabled. It is not so much fear of being unable to do things, but more of being rejected, unable to form normal relationships, left on the sidelines, being dependent on other people who do not understand your needs, losing control of basic choices in day-to-day living. That is what disability seems to amount to and that is why it is feared. And so this fear is expressed in prejudice, awkwardness, cold-shouldering, pretending the problem does not exist, which all serve to perpetuate the cycle. The crucial task is to break the cycle.

We can start by accepting that disability exists. It is part of human life, part of the way things are. Let us engage with it, enquire into it, make friends with it. Disabled people do this from the inside, people who are not yet disabled need to do it from the outside. One way or another we cannot ignore it; if we ignore it, we place ourselves outside the human condition in some kind of unreal, aseptic world that cuts us off from our very humanity.

Privacy exacts its costs. How quickly it turns to loneliness and alienation. Our defense against one kind of suffering, ironically, turns out to have invited in another. We somehow feel safe from the troubles of the world, but we also begin to feel dry, empty and alone in our isolated havens. Gone is the mutuality and spontaneous support that arise naturally when lives are led in common. With doors closed to the pain of others, we banish that which would release our compassion and engagement with life. We need heart-to-heart resuscitation.³

Integration means recognising differences

Impairment does entail a loss. But let us not be misled: it is mainly a loss when measured against the standards of an able-bodied world. That is the point. We have a notion that disabled people are more dependent than non-disabled people. We think that a wheelchair, for example, underlines this dependency. But for most people in the able-bodied world material success is measured by the number of gadgets on display in a person's house. A TV must come with a remote control so that you don't even have to move from your chair to change the channel — a feature of modern life (at any rate in the West) that is now accepted as standard. A high salary is used to buy a state-of-the-art motor-car with electric windows, temperature control at the touch of a button, and ergonomically designed seats to avoid back-ache in the exhausting business of sitting down. Such a car is admired, while a wheelchair — by comparison an extremely utilitarian mobility device — is derided as a symbol of dependency. But who, we should ask ourselves, is dependent?

The world we inhabit has been designed by able-bodied people, and it is they who have in large measure invented the 'problem' of disability. In truth, dependency and inter-dependency are part of the substance of all our lives to a high degree, and yet disability is seen as bringing extra dependency. The only thing that makes disabled people more 'dependent' is that they have fewer choices.

But saying that confronts us with another paradox: the difficult question of integration and separateness. If the 'problem' of disability is an artificial social construct and would be instantly solved if the able-bodied could only get rid of their tunnel vision, then what is all this about a separate disability movement, and even a separate disability culture?

'The problem,' wrote the Bengali poet Rabindranath Tagore, 'is not how to wipe out all differences, but how to unite with all differences intact.' Why should everybody be the same? Real integration of disabled people can be achieved only on the basis of a full recognition of their differences. This in turn depends on their being able to make a free choice to identify themselves as a distinct social group. How can disabled people express and celebrate their different-ness? By coming together in groups, by forming a movement, by developing their own culture, which then becomes part of a multi-cultural society.

In an early chapter of this book we considered the two extremes of a fascist society in which uniformity and conformity are prized and difference is damned, and (in contrast) an open society in which the whole spectrum of human life and experience is celebrated. A carnival in which everyone wears the same costume would be no fun at all; it would be a contradiction in terms: a carnival is made a celebration precisely by the diversity of the costumes. To prepare their costume and then come forth to join in the general celebration, people need to be able to 'retire back into their chambers' (as Jabulani Ncube of Zimbabwe put it in Chapter 6). Retiring into the chamber and coming forth are both necessary parts of this process: there is nothing to come forth with if the costume has not been prepared in the chamber first.

Disabled people need to be able to 'retire into their chambers', that is, meet among themselves as a distinct group, in order to develop their own culture as a contribution to the sum of human experience and expression. It is in such a distinct group that change can begin, where disabled people can feel the strength of being with others faced with the same difficulties, where an actual experience of empowerment can happen through a shared understanding. Change does have to start with disabled people themselves in this way: the case studies in this book illustrate that point above all others. With this new strength they are then better equipped to come forth and make their contribution to the totality of human experience. 'The celebration of difference, we will then discover, *is* the celebration of

humanity, of being members of the human family.⁴ The same is true for any group of oppressed people.

Links with other liberation movements

It is important to see the connections between disability issues and other struggles for social justice, for example the women's movement. The double disadvantage which disabled women experience has been touched upon in various places in the book, but not given anything like the treatment it deserves. It is a failing. I myself was not sensitive enough to the way that gender-imposed inequalities operate among disabled people, and I did not insist sufficiently on finding disabled women to interview.

The reason why the women's movement has not previously dealt with the issue of disabled women is, according to one writer, because 'they reinforce traditional stereotypes of women being passive and needy',⁵ the very stereotypes from which feminists are trying to escape. That is also a reason, I suspect, why other groups struggling for their own liberation have not generally linked up with the cause of disability in any significant way. But that too is part of the ignorance and prejudice that pervades the whole of the able-bodied world about disability.

Other parts of the women's movement have recognised the obvious links, not only with disability, but also with all other struggles for social justice by oppressed people. A letter to the magazine *Spare Rib* of September 1992 puts it succinctly:

... if you really are involved in the cause of ... feminism, whether you like it or not you are also involved in the ANC, Intifada, gay liberation, disabled people's rights and similar 'causes'. Whoever the oppressed and the oppressor are, there is only one freedom.

It is clear that disability does lie in close parallel with other liberation struggles, and other such struggles have something to learn from the disability movement. The women's movement (as I understand it) is not trying to make women more like men. It is, on the one hand, trying to define, express, and celebrate 'womanliness' as an essential and integral part of the human experience, and on the other hand to show that a sense of a common humanity must regard the person inside the body as of far greater importance than the body itself. So with disability.

Able-bodied women can learn from the disabled, who have had to learn this before they can truly cope, that the physical body is not as important as the person that lives inside; ... that every woman who is honestly involved in her own personal growth is making a contribution to the women's movement whether she is aware of it or not.⁶

The role of able-bodied people

So what about me as a non-disabled, 'temporarily able-bodied' person? What is my role? One of the ways in which segregation has been most blatant is in assigning 'specialists' to 'look after' disabled people, as though non-specialists are incapable of doing so. This is all part of the baggage of the medical model, where control over health is kept in the hands of trained professionals. Besides disempowering disabled people, it disempowers able-bodied people, who feel that they 'don't know enough' to 'deal with disability'. This is nonsense. Micheline Mason writes:

The truth is we do need you, not to be the 'experts' or managers of our lives, but to be friends, enablers and receivers of our 'gifts' to you. We need you to admit cheerfully what you don't know, without shame; to ask us what we need before providing it, to lend us your physical strength when appropriate, to allow us to teach you necessary skills; to champion our rights, to remove barriers previously set in place, to return to us any power you may have had over our lives. We may also need you to remind us of our importance in the world, and to each other, at times of tiredness and discouragement. We can live without patronage, pity and sentimentality, but we cannot live without closeness, respect and cooperation from other people.⁷

The truth is, as well, that able-bodied people need disabled people in order to re-engage with the totality of human experience. Unless we can relate constructively to disabled people, we ourselves are impoverished. It is a question of partnership.

Ruth and Stephen

Towards the end of my research for this book I found a remarkable example of such partnership.⁸ Ruth Sienkiewicz-Mercer has severe cerebral palsy, hardly any movement in her limbs, and no speech. For thirteen years, from the age of six to nineteen, she lay in a State

institution in Baltimore in the USA, treated like an object with no mind, no thoughts, no feelings, no opinions, no wishes, no dreams. The only attention she received in all that time was to be fed and toileted. Through all these years inside this immobile and silent body her lively mind kept track of time, people, events, characters, her own emotions and development — without being able to communicate any of this; her 'carers' had not the faintest inkling that anything was actually going on inside her head. She was classified as an 'idiot'.

It was not until a volunteer, Stephen Kaplan, interested in the problems of the speech-impaired, realised that she was bursting to say something that Ruth was 'discovered' as a person. By using word boards held up in front of her and asking her to say 'yes' by raising her eyebrows or 'no' by pursing her lips, he drew from her her story, word by word and line by line, and set it down. The whole writing took years to complete, covering perhaps a few paragraphs in each session. The book they wrote together is rich in texture and full of penetrating insights from a person who did all her learning and growing in almost complete isolation. Without Stephen, Ruth would never have emerged, doomed for life to be a silent, imprisoned witness of a world that refused to acknowledge that she even had something to say.

Ruth's contribution to the sum of human experience is profound. If anyone still has lingering doubts about the value of an individual severely impaired life, I suggest that this book will put those doubts to rest for ever. That is the good news. The bad news is the shock of realising that Ruth is one of the lucky ones: how many other Ruths are there who have never been 'discovered', who are living their lives trapped inside a body with no way of relating to people on the other side of it, and assumed to have nothing to say?

Ruth's story illustrates all the major issues raised by disability. It is about the ignorance, prejudice, and fear that create the climate of hostility experienced by disabled people; it illustrates dramatically the dismal paucity of the medical model and the institutional approach; it reveals the profound insights that come as a result of suffering; it reveals Ruth as indeed someone extremely special — but not as someone claiming to be a heroine. But above all, it is about an empowering and liberating relationship, a relationship free of all prejudice and fear, and full of understanding which set her free; it also brings us back to the struggles by other oppressed groups for recognition, dignity, and liberation, particularly the women's movement.

The examples of social action recorded in this book, like the pressure for change on the Abu Samra institute in Tripoli or the formation of disability *sanghams* in India, illustrate what is possible when disabled people and able-bodied people work together with respect and understanding. Disabled people are engaged in a liberation struggle, but a liberation struggle that does not presuppose a zero-sum game — *if you win, I lose*. It is *if you win, I win*. The liberation of someone like Ruth, or the sense of their own worth newly discovered by disabled people in an Indian village, is a liberation which enriches us all. Such liberation is possible once disabled and able-bodied people understand that how we relate to each other is the key. We all, both able-bodied and disabled people, need to be liberated from our fears and prejudices, our misunderstandings and tunnel vision, and our ability to oppress each other. It is a process of liberation that continues for the whole of our lives.

*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.⁹*