PHASE 2: DISCOVERING THE PERSON IN 'DISABILITY' AND 'REHABILITATION'

by V. Finkelstein

The past ten years have seen great changes in the position of disabled people in this country. This period has been called the age where rehabilitation has come into its own, where the rights and needs of disabled people have been increasingly recognised, and so on. However, there is still some confusion about where this is all leading, what has really been achieved, and even, at times, what it is all about. Mary Greaves, for example says, on integration: 'We who are disabled all talk long and glibly about "integration" and "segregation". Many of us are not quite clear what we mean – I certainly don't – at least all the time! ... First let me be quite clear and unambiguous – I want to be integrated – whatever definition is given' (1). Equally undefined, in another area of disability, is this description of DIG's position on disability: 'DIG is not concerned with the cause of disability but with the economic consequences' (2). However, if causes are not understood then the consequences may be equally misunderstood.

It is my belief that there is a growing awareness of the social nature of disability and that overcoming outstanding problems requires social solutions. Basically this means the action of the disabled for themselves (together with others) rather than, as before, others acting for them. I see the rapid growth of organisations and associations for, and by, the disabled over this period of time, as a search for greater involvement by disabled people in their own affairs. Of particular interest is the growing number of organisations that have been started by disabled people, some of which now confine active membership to disabled people. It seems we are in transition from the era of medical rehabilitation, and doctor's domination over the lives of disabled people, to that of the issues of social integration and the active participation of disabled people in their own affairs. Ideas in all the areas of disability also need to be seen to be connected – rehabilitation, institutional care, special education, etc.

Many people have written about these changes and the need to rethink some of the basic ideas. Many mention the idea that we have reached the end of one stage and now enter a new one. Louis Battye, writing about the present position in Cheshire Homes says: 'Twenty years ago the homes represented a brilliant pioneering venture, a new concept for the disabled. But they have been overtaken by events ... The *avant-garde* has become the old hat' (3). He goes on to mention that 'management of many homes is largely in the grip of small self-perpetuating middle-class circles' and that 'there is little genuinely democratic control'. He calls for greater choice by disabled people for themselves: 'They should have the right to choose, within the limits of their disabilities, the kind of life they want to live' and concludes: 'the Foundation would do well to engage in a radical rethinking of its traditional policies. It might indeed be said that phase one of its great work to better the lot of the disabled, at least in this country, has now been completed. If phase two should prove as big an advance as its predecessor it will earn even more gratitude from even more people'. *But what is to be phase two?*

To my mind phase two begins with greater involvement by disabled people in all their problems; medical, social and economic. Here are what some writers have said; John Koarty from Australia: 'I do not condemn able-bodied people; what I am trying to do is to encourage invalids to take a more active part in their own affairs, to be prepared to make sacrifices in time and energy and to become more involved in planning their own welfare' (4). Neville Vandyk, on rehabilitation says: 'What cannot be over-emphasised is the need for the patient

to participate in discussions about his own future and prospects. Too often he is regarded as the raw material to be processed by the various professional practitioners as they consider best' (5). Professor Brattgard, President of the Fokus Society in Sweden, puts it this way: 'The only way of achieving the right attitude to the disabled is to accept him as a collaborator and fellow member of the community; a man who can take full responsibility for his life and his actions' (6).

Dr. Agerholm has suggested that disabled people actually played a greater role in giving ideas to rehabilitation than many others might think: 'The best rehabilitation ideas were usually theirs, and they worked out in incontrovertible detail their own practical solutions to their own practical problems'. Like Professor Brattgard, she goes on to say: 'I am convinced that the mere fact of disability – that a person is disabled does not give us the right to deprive him of his right to decide for himself what risks and hardships are acceptable, and so to continue to determine his own fate like his able-bodied fellows' (7). That was said in 1964. By 1972 Dr. Agerholm was writing, rather over-optimistically: 'One important hurdle does seem (or did until the regressive Tunbridge Report tried to put back the clock and put the handicapped back into hospital) to be being overcome, viz., the idea that handicap is a medical problem and its management belongs to the Health Service. The vast majority of handicap problems are mainly of social, educational, employment, architectural, and "care" character. Doctors and the remedial professions contribute constructively when they abandon the doctor-patient therapist-patient role relationships and simply offer a "rehabilitation" service' (8). However, I believe that if things are really to change in rehabilitation it is not enough that doctors abandon old roles (while they keep their old powers) but that both the disabled patient and disabled people really be given a say in the rehabilitation team as full and equal members.

Recently some organisations of the disabled have championed the greater professional involvement of the disabled in society and rehabilitation. Lady Masham says this of the newly formed Spinal Injuries Association: 'The Spinal Injuries Association feel that some of their members, all who are paraplegics or tetraplegics, could give great help to new patients by counselling. In time we hope that some members would become part of the Rehabilitation team and that a much more comprehensive planned rehabilitation programme would be available to all patients' (9). Similarly, the Association of Disabled Professionals says it is concerned with: 'Improving the rehabilitation, education and training facilities and opportunities for the disabled, and assist them by encouragement and example to develop their physical and mental capacities to the full and promote their entry into the professions and their full participation in and contribution to society' (10).

Recognition of the need for disabled people to be involved in their own affairs has by no means been fully accepted by the medical profession. The recent Tunbridge Report remains the best example of how difficult it is for old attitudes to die in the profession that dominates the field. Although Sir Ronald Tunbridge can say: 'Only in recent years would government seem to have begun to appreciate the importance of social aspects and the quality of life available to the rehabilitee ...' (11), it is precisely the lack of these aspects in his report which was most severely criticised. Dr. Agerholm called it the 'regressive Tunbridge Report' which 'tried to put back the clock' (8), and Selwyn Goldsmith says, simply: 'Last October, at a meeting arranged by the Central Council for the Disabled the Tunbridge Report was dissected and damned' (12). He went on to summarise what various people said, and there remains little doubt about the overall criticism of the medical onesidedness of the report.

Similarly, Dr. Nichols looks at rehabilitation through rather medically coloured glasses. He refers to the Tunbridge Report uncritically and although he goes on to conclude: 'Thus, the rehabilitation ideal involves a comprehensive understanding of the nature of the disability and

clear decisions as to the real problems which need solving, whether clinical, functional, psychological, educational or social' (13), he still errs in placing the medical profession as dominant: 'To the extent that rehabilitation is concerned with disability and restoration of capability it is not a "speciality" within medicine, but a function of all medicine and *its associated disciplines*'. (my emphasis). To my mind the social aspect should dominate (under the control of disabled people) with medicine being one, of the many, associated and equal disciplines. While he does say: 'the first problem is to help patient and doctor diagnose, assess, acknowledge and accept the disability', actually this is not an equal partnership. Only the patient is expected to understand and accept the disability, while the doctor does not need to adjust *his* or *her* views. All rethinking is on the patient's side!

In contrast to Dr. Nichols who advocates the disabled person 'accepts the disability', Paul Hunt, who has written widely on disability and who is a consistent advocate of 'consumer' involvement, says about institutions: 'What changes in society are required if severe disability is either to be eradicated or to become no bar to full social participation?' Going on to call for disabled people's views he says: what is 'needed was to have the views of people who are themselves actual or potential recipients of institutional care. Their ideas on the situation are more important than anyone else's, but are often least taken account of by administrators, planners and politicians' (14). Later a group of disabled people who sent in their views went on to form the Union of the Physically Impaired Against Segregation. Earlier he had become aware of the need to present new ideas on disability and to get away from a purely physical (medical) approach: he says this about the writers who contributed to his book, Stigma: 'We provide, too, an example of the way increasing numbers of handicapped people are thinking about their predicament. The distinctive feature of this development is an awareness that there is really no such thing as a disabled person, only *people* who have disabilities. This may seem a truism. Yet the shift of emphasis from the disability to the person has far-reaching implications' (15).

I should like to sum up the views of all these writers who call for more social involvement by disabled people. Somewhat like parents who take responsibility for their children's actions, the medical profession has nurtured disabled people, saved their lives and tended to make their decisions. Just as the child grows to adulthood and demands independence and the right to lead her or his own life so, too, disability has come of age and disabled people, in society or as patients, must be increasingly recognised as the spokesmen for themselves, having the right to make their own decisions and their own mistakes. Modern medical (and rehabilitation) practice which fails to recognise this takes on the role of the neurotic parents who cling to their children as the justification for their existence. We have reached the cross-roads in disability where new ideas, new approaches, new solutions and new definitions are needed. This is the implication, to my mind, of Mr. Hunt's shifting emphasis from disability to the person.

The need for new definitions, which result from the changing social position of disabled people has been approached by Amelia Harris and her colleagues, in their Survey for the Office of Population Census and Surveys. Up till now words like 'cripple', 'invalid', 'handicapped', etc., were all considered to mean more or less the same, except that some of the words were more 'nasty' than others. Now Amelia Harris has given definitions which describe different aspects of the problems of the disabled, and for the first time leave proper room for a social definition, although, I feel, this is still not clearly and adequately defined: '*Impairment*' is defined as 'lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body'. '*Disablement*' as 'the loss or reduction of functional ability'. '*Handicap*' as 'the disadvantage or restriction of activity caused by disability'. – quoted by Sir Ronald Tunbridge (11).

From this it would seem that when an impairment results in a disability (like losing the functional use of one's legs and being unable to walk) and this *causes* a disadvantage, then one suffers a (social) handicap. But the cause of the handicap is still seen as within the individual with the impairment. I should like to suggest two changes to these definitions. Firstly, that the cause of handicap lies within the society which disadvantages impaired people by taking no, or very little, account of their physical condition and consequently does not provide the solutions – for example, providing ramps for wheelchair users who are unable to walk up steps. As I see it, the handicap is *caused* by having steps into buildings and not by the inability to walk. My definition attempts to give a truly social emphasis. it gets away from the individual causing his own disadvantages which he then also suffers as a handicap. In addition, if we see the disadvantages resulting in handicap as caused by the way society is arranged in its details then changing these, opens up the possibility of overcoming handicap (*not* adjusting to it).

Secondly, I suggest changing the definitions of the words *handicap* and *disability* around. In this way a person is disabled when he or she is socially prevented from full participation by the way society is arranged (in the broadest sense). I prefer this, because this 'social' association to the word 'disabled' seems to be more common than to the word 'handicap'. The 1950 Constitution of India, for example, clearly gives the word 'disability' a social definition in its reference to the caste of Untouchability: 'The enforcement of any disability arising out of Untouchability shall be an offence punishable in accordance with law'. With these definitions I see the possibility of overcoming disability, not by the action of doctors or other individuals but by the re-arrangement of society, with the active participation of its physically impaired members.

In order to make my concept of the social nature of disability more clear I should like to argue by way of an imaginary example which turns the world upside-down. Let us suppose that those who advocate Het Dorp type solutions to the housing problems of disabled people got their way and carried out the scheme to madness. They collected together 1,000 or more disabled people who were all wheelchair-users and placed them together in their own village where they had full management and democratic rights. We will suppose able-bodied people do not often visit the village and that the wheelchair-users control all aspects of their lives. They work the machines that clean the streets of the village, they run their shops with special aids, run their own colleges of education, banks, post offices, etc. In fact for the villager, being in a wheelchair, is like anyone else in the world of people that she or he comes across in his daily life. He sees wheelchair-users on television and for all purposes the able-bodied are people only rarely seen and little understood.

In the course of the life of the village the wheelchair-users design their own buildings to suit their own physical needs. One thing the wheelchair-user architects quickly discover in this village is that since everyone is always in wheelchairs there is no need to have the ceilings at 9ft. 6in. or the door heights at 7ft. 2in. Soon it becomes standard practice in this village for doors to be designed to a height of 5ft., and ceilings of rooms to be 7ft. 4in. Now everyone is happy in this village, all the physical difficulties in the environment have been overcome and this little society has changed according to the physical character of its members. At last the buildings are truly in tune with their needs.

Let us say that when all the adjustments had been made and become fixed, in the wheelchair-users' society, a few able-bodied people had, through no choice of their own, to come and settle in this village. Naturally, one of the first things they noticed was the height of the doors and ceilings. They noticed this directly, by constantly knocking their heads on the door lintels. Soon all the able-bodied members of the village were also marked by the dark bruises

they carried on their foreheads. Of course, they went to see the village doctors, who were, naturally, also wheelchair-users. Soon the wheelchair-user doctors, wheelchair-user psychiatrists, wheelchair-user social worker, etc., were involved in the problems of the able-bodied villagers. The doctors produced learned Reports about the condition of the able-bodied people in society. They saw how the bruises and painful backs (from walking bent double so frequently) were *caused* by their physical condition. The wheelchair-user doctors said these able-bodied people suffered a malfunction of their functional abilities which resulted in a handicap. This handicap caused a disadvantage or restriction of activity which made them disabled in this society.

Soon special aids were designed by the wheelchair-user doctors and associated professions for the able-bodied disabled members of the village. All the able-bodied were given special toughened helmets (provided free by the village) to wear at all times. Special braces were designed which gave support while keeping the able-bodied bent at a height similar to their fellow wheelchair-user villagers. Some doctors went so far as to suggest that there was no hope for these poor sufferers unless they too used wheelchairs, and one person even went so far as to suggest amputation to bring the able-bodied down to the right height!

But one day, when the able-bodied were sitting together and discussing their problems they realised that they were never consulted by the wheel-chair-users about their problems in this little society. In fact they realised that there may be solutions to their problems which had never occurred to the wheelchair-users simply because they never looked at the problems in the same way as those who had the problem. In fact, it occurred to these able-bodied disabled people that perhaps the *cause* of their problems was not at all in themselves because they were physically abnormal (by being too tall) in this village, but because the society took no account of their physical condition in its social organisation. They began to see a social cause to their problems and a social solution – they suggested that the door and ceiling heights be changed! Of course some of the village wheelchair-users thought the able-bodied disabled were failing to accept their disabilities and had chips on their shoulders because they argued so strongly for social change and a change in attitude by the wheelchair-users. The able-bodied disabled even argued that perhaps their disabilities could be overcome (and disappear!) with changes in society.

I hope this story helps to clarify what I mean by the social nature of disability and to clear the air for phase two in the field of disability. I do not mean, in this example, that the only way of overcoming disability is by altering architecture but by also using all scientific inventions, aids and gadgetry which will enable the problems to be solved. Clearly, for the social aspects to be examined more fully in a new way, and society itself to make changes, disabled people have to become increasingly involved in the solution of their problems and, when patients too, be encouraged to take an increasing part in rehabilitation on an equal basis with professionals. Until there are these changes in medical opinion and practice, I am afraid the disability field in this country will remain static, frustrating for the 'consumers', and increasingly backward compared to other countries where disabled people are encouraged to take an ever greater socially active role.

Will the incumbents in the two Chairs of Rehabilitation in the UK take note of changes in the social position of disabled people and encourage their involvement in the rehabilitation process, or will they promote the old medical concepts and try to hold on to the medical profession's domination in the field of disability? Perhaps we can now move on to phase two full of hopeful expectation for the future where disability will, in Paul Hunt's words, be 'eradicated'.

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