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1.   The crisis in confidence

In June 1980 at Winnipeg in Canada, Scandinavian organisations of disabled people presented a proposal to the 14th World Congress of Rehabilitation International (RI) which would give organisations of disabled people a majority influence in RI. "After a long and heated debate, the proposal was turned down" (l)(2). RI is one of the premier international organisations concerned with issues faced by disabled people. It is an organisation with various interests and principally represents professionals, but also service providers, government officials and disabled people themselves. The rejection of the proposal for disabled people to have a major say in RI reflects, I believe, at an international level the closing stages of a long malaise – namely the loss of confidence in the ability of professional workers to adapt to the changing. situation of disabled people. This loss of confidence has reached crisis proportions and is expressed in two developments (10).

Firstly, in response to what is felt as a lack of movement in meeting unsatisfied needs disabled people have increasingly formed their own organisations in order to put pressure on the service providers to address these needs and make provision for them. In the absence of such responses the organisations have inevitably begun to make their own provisions (such as counselling services, independent living centres, or Fokus-type housing schemes). The rising number of organisations of disabled people, therefore, can be seen as the spontaneous response to the lack of confidence in the ability of professional workers to put their house in order and address the issues which disabled people see as requiring immediate attention. The loss of confidence in the professions is at two levels: (a) it is felt that certain services (such as, for example, 'personal attendants' to enable disabled people live in their own homes in the community) will not materialise out of existing professional approaches and perceptions of the problems, and (b) it is felt that the attitude of mind cultivated by professional workers goes against a dynamic relationship between those who help and those who are helped which is adequate to the modern situation. It is believed, that this attitude leads professionals to set limited objectives for their patients and clients, who are then treated, manipulated, have things done to them and for them, and are managed and cared for. It is this attitude of mind that is the despair of disabled people and which leads to serious suggestions that only disabled people can educate and train the new workers for the future services.

Secondly, professional workers sensitive to the schism between themselves and their disabled clients, are articulate in expressing a need for new ways of relating to their disabled clients and patients. The Jay Report (4) for example, refers to just such a need for new perspectives amongst professional workers with mentally handicapped people. This is further reflected in the call for new education and training schemes that will equip future professional workers for the evolving services. The call for new curricula in professional courses is not merely a call for update courses in order to keep professional workers in touch with the latest developments but a call for an overhaul of some basic aspects of their existing courses. This rising anxiety about aspects of existing courses seems to be in response to the falling confidence of disabled clients who are increasingly turning to alternative forms of help and self-help. The Central Council on Education and training of Social Workers paper "Social Work: people with handicaps need better trained workers" (5), for example, refers to professional anxiety about their ability to meet the changing needs of their disabled clients.

Of course, the general public's increasing lack of confidence in the services provided by professional workers also plays its part in influencing the crisis of confidence between disabled people and those who work with them. This is obviously not helped by the financial cutbacks. Scarce' resources intensify the perception of problems which, in more affluent times, can be obscured by the provision of material goods. The fact that some professionals, for example some who are working with mentally handicapped people in small community residential projects, have been in the forefront of effecting change in the way helpers work with those they help does not alter the argument. Such people are few in number and often have had an uphill battle getting their projects off the ground.

The inertia of established professional authorities in disability in responding to the voice of disabled people (expressed as – "We demand the right to speak for ourselves at this and every other gathering" (2)) should not be underestimated. The so-called "Charter for the 80s" for example, and much heralded by some as a "major contribution to the International Year of Disabled People" (5) was approved by the Assembly of RI at its l4th World Congress – the very Congress that rejected the proposal for organisations of disabled people to have a majority say in RI! How can' disabled people have confidence in such Charters which declare aims such as "to take all necessary steps to ensure the fullest possible integration of and equal participation by people with disabilities in all aspects of the life of their communities (5, my emphasis), when the bodies that approve such documents treat these aims indifferently.

2.   Redefining the problems

The draft Constitution of the Disabled Peoples' International cites part of the contemporary problem faced by disabled people as being related to the fact that "disability has too long been viewed as a problem of the individual, and not the relationship between an individual and his/her environment" (6). In the discussion between the Disability Alliance and the Union of the Physically Impaired Against Segregation (UPIAS) Paul Hunt, speaking on behalf of the latter organisation, put the social perspective of disabled people even stronger. He said: "disability is a situation, caused by social conditions, which requires for its elimination ... (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people" (7). It is precisely lack of confidence in the willingness and ability of professionals to help in the promotion of such control that characterises the contemporary helper/helped relationship. But if such a lack of confidence now exists this was not always so. We have therefore, to ask what is the origins of this contemporary attitude between disabled people and those employed to help them and why is it that the professions failed to anticipate the emergence of this crisis and take corrective action. I believe that the answers lie in the way in which the professions came into being in order to help a group of people who had already become socially isolated, cut off from a source of income and totally dependent on others to solve their problems.

The details of the process whereby those with physical impairments were sifted out of society and placed into the hands of a specially educated and trained group of helpers awaits future research. Nevertheless, if we take an historical approach it seems possible to sketch the broad areas of development:

(a)   at the infancy of capitalism physically impaired people, when they survived the harshness of the conditions of their environment, lived as "cripples" within the community. Perhaps they were dependent upon Church assistance from time to time, but nevertheless they were not totally segregated from society. As long as home based small craft industry (such as weaving) existed there was the possibility of the surviving less severely impaired cripple

contributing to the economic life of the family by operating, for example, a hand loom or spinning wheel (the picture of the lame girl sitting at a spinning wheel must be familiar to many). The use of relatively small machines in home based industry raises the possibility of minor adaptations to suit the individual and, of course, travel to work did not arise!

(b)　when the effects of the industrial revolution worked through the system over a period of about 100 years there was, in my view, a profound change in the lives of cripples. The essential point of departure seems to be that large machines are designed not to be used by a specific individual, but by <u>any</u> worker. Thus design criteria for the manufacture of machines were established on the basis of the "average worker". In addition, these machines were, in time, housed in special buildings, again designed for access by the average worker, and sited within reasonable travelling distance from the average workers' home. If people had to move in order to settle within travelling distance to a factory then the houses designed for them were for workers – i.e. those of "average" physique who would work the machines or work in the mines, etc. Thus, it would seem the industrial revolution had a twofold effect – it elevated the importance of average physique so that this became a major criterion for earning a living and it deprived those of impaired physique from the socially normal means of obtaining an income. There could be no fall back on home craft industries since these industries were being destroyed economically by the more efficient factories. The industrial revolution, therefore, sifted out of the community its cripples and transformed them into disabled people – that is society disables its physically impaired people as a result of the way its production and source of income is organised (7).

We can suppose that the sifting process was hastened by the increased population, greater success in sanitation and improved medical practice. All this would have enabled more physically impaired people survive. In time efforts were made to segregate unemployed disabled people from unemployed able-bodied people. Incarceration in institutions or isolation in back rooms of homes became the lot of disabled people. As beggars were pushed off the streets the way was paved for the 20th century rise in the caring professions working with disabled people. By the time these helping professions took their modern form disabled people had effectively been segregated from mainstream society and this segregation must have seemed to be the perfectly natural consequence of the individual's impairment. That it was the consequence of the industrial revolution was lost in history. The professions, then, came into being and decided how their members were to be educated and trained, on the <u>fact</u> of segregation, their clients' loss of an economic means to a livelihood, client dependency, a limited perspective for their clients' ability to participate in society and to control their own lives, and a belief in the view that disability was a problem of the individual. In other words, the fundamental assumptions underlying correct practice to be inculcated in professional workers rests upon the fact of segregation.

(c)　the technological revolution now unfolding has not only made it possible for the most severely physically impaired person to work and earn a living on par with able-bodied workers but undermined the basis of the former helper/helped relationship. If, after all, sophisticated computers and modern industrial wealth can enable a severely physically impaired person to take control of a very large rehabilitation service which once informed him that he was unemployable, as happened to Ed Roberts in California, U.S.A., then the traditional basis for the education and training of professional workers in disability is historically at an end. Failure of the professions to adjust to this fact means that they become out of step with history and eventually this leads those who are meant to use their services to lose confidence in these helpers. (8 and 9).

3.   Resource based rehabilitation

If society, through the technological revolution, now has the means to reintegrate its disabled people and if, as disabled people are saying, integration means taking control over ones own life and if disabled people do need continuing assistance from others then the basis of the future helper/helped relationship has to undergo profound transformation. In the first place, as UPIAS says, the basis of professional practice must rest on an assumption of integration and a commitment to promoting control by disabled people over their own lives. Since the lives of disabled people also depends on the actions of helpers, control over the education, training and role of such helpers needs to be vested in disabled people (quite aside from the need for more disabled people to enter the professions).

What this means in practice is that the role of the professional worker in rehabilitation, for example, needs to change from management of the patient to that of being a resource for the patient to use in reaching his or her own goals. The suggestion that professional workers in rehabilitation should become a resource to be utilised by disabled people is not a suggestion that professionals should become passive and all the onus for innovation, assessment, decision-making, etc. should now fall on the shoulders of disabled people. Professionals acting as a resource to be used by others need, special education and training so that they are able to <u>promote</u> (7) control by disabled people. To promote something is to take an active role and, in this case, an active role in helping disabled people learn how to use professionals as a resource in solving the goals of rehabilitation. To do this professional workers will need new communication skills, 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 issues. Is it, for example, important to learn to use callipers and crutches, or to lip read, or is it firstly important to isolate the purpose of these activities and encourage disabled people to find the most appropriate solutions which will enable them to move from A to B by, say, making the environment accessible to wheelchairs, or finding more efficient ways of getting computers to facilitate communication between deaf and hearing people? The need is for new relationships to develop between helpers and those they help.

The endemic squabbles between rehabilitation workers about professional boundaries and the familiar farce of professional 'teamwork' can only be put at an end when all the workers and facilities in rehabilitation become resources in a process of self-controlled rehabilitation. Those familiar with the concept of models will recognise that what is being advocated here is a shift from the medical model to an educational model of rehabilitation. This approach can be called "resource based rehabilitation". I believe that Britain has the infrastructure of services for just such a comprehensive resource based rehabilitation service and that the implementation of such a service faces only one barrier – namely, those attitudes of professional practice which formed the built-in assumptions of the professions when they were newly created upon the basis of the segregation of disabled people.

Such attitudinal barriers can, of course, be insuperable and disabled people will have to continue the road already taken in starting to create new services and professional helpers to meet their self-defined, needs. The prospect of established workers in the field joining this development is the challenge faced by the existing professions.

References:

(1)   MILLER, K.S., CHADDERDON, L.M. AND DUNCAN, B. (Eds.) (1981) "Participation of people with disabilities: an international perspective": University Centre for International Rehabilitation and Rehabilitation International.

(2)   STEERING COMMITTEE OF THE DISABLED PEOPLES' INTERNATIONAL (1981) pamphlet.

(3)   CENTRAL COUNCIL FOR EDUCATION AND TRAINING IN SOCIAL WORK (1974) Paper 5: "Social work: people with handicaps need better trained workers"

(4)   REPORT OF THE COMMITTEE OF ENQUIRY INTO MENTAL HANDICAP AND NURSING CARE (1979) H.M.S.O.

(5)   CHARTER FOR THE 80s (1980) IYDP (England) with UK Committee of Rehabilitation International.

(6)   STEERING COMMITTEE OF THE DISABLED PEOPLES' INTERNATIONAL (1981) draft Constitution.

(7)   UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (1976) "Fundamental principles of Disability"

(8)   FINKELSTEIN, V (1980) 'Attitudes and disabled people: issues for discussion' World Rehabilitation Fund.

(9)   FINKELSTEIN, V (1981) "Disability and the helper/helped relationship: an historical view" in BRECHIN, A., LIDDIARD, P. and SWAIN, J. (1981) "Handicap in a social world". Hodder and Stoughton Course Reader for the Open University course – The Handicapped Person in the Community (remade)).

(10)   UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (1981) "Editorial" in Disability Challenge.