

## **RESEARCH REQUIREMENTS**

*V. Finkelstein*

Published in

Singleton, W.T. and Debney, I.M. (eds) (1982) *Occupational Disability: The Approaches of Government, Industry and the Universities*. MTP Press Ltd.

As the Chairman of an Open University course called 'The Handicapped Person in the Community' (this course is presented each year to a large number of professional and lay people concerned with the subject), I intend in this chapter to present the issues and problem areas which in my experience are of concern to us in our endeavours to see the maximum integration of disabled people. Such issues and problems should naturally generate research and, I suppose, pose particular requirements to ensure their solution. I hope to give some pointers as to where research is needed and may be fruitful and what pitfalls we should keep in mind when deciding our methodology.

My central contribution to the discussion, however, is concerned with the conceptualisation of research (and the non-handicapped worker's contribution to research practice) on disabled people by, at least some, disabled people themselves. It is patently obvious that, as our society has evolved freeing larger numbers of people to work in the support services and as environmental control technologies have improved, so too the numbers of disabled people taking up occupations in the general field of disability has increased. I believe there are long-term profound implications in this development which are already becoming manifest. For example, the first question confronting a disabled person who enters a profession working with disabled people is often couched in terms of a polarization between personal and professional interests i.e. is there to be a marriage (or divorce) between the interests of the individual acting as a professional worker with (other) disabled people and the interests of the individual expressing his or her own needs as a disabled person? In my view this poses the need for research into the origins and nature of professional conceptualisations of disability.

### **Points from earlier contributions**

Before pursuing my central theme I should like to mention a few points which seem to emerge from earlier chapters in this book, and which I believe enhance the points I wish to make later.

Dr Duckworth (Chapter 3) gave us an overview of the prevailing thinking, at least in this country, about terminology currently in use in this field and about some of the definitions which have been floated and gained more or less currency amongst professional workers. One cannot help being struck by the number of schemes being promoted and, in particular, by the lack of precision that has so far been achieved. When it comes to terms which are more or less wholly related to the physical characteristics of the individual who is disabled there does seem to be some movement towards consensus – e.g. the term 'impairment' seems to generate the least controversy, although its structural relationship to the overall model of disability varies considerably from model to model.

Most problems, however, seem to occur when attempting to define terms which include functioning of the human body; both in the individual state (e.g. 'walking') or in a social setting where activities of daily living are carried out (e.g. 'dressing'). The terms 'disablement' and 'handicap' appear to be the rogues with the latter generating the greatest disagreements and, more significantly, being the most elusive for precise assessment.

Here the point is made that precise definitions of these terms is necessary so as to facilitate consistent research and more accurate assessment results. The point is that it is precisely this

operational goal that is not being achieved to date by these definitions. Obviously, if I am to point out lines for research, here is one area in which we should encourage more thinking and investigations.

But I believe one possible reason for the present problem in achieving precise definitions for handicap and disability lies in the failure to contemplate the assumptions that are automatically made by professional workers when problems (of disability) are presented to them. At this moment I only want to say I believe disablement (or handicap, if this is the preferred term) defines a relationship between an individual with a physical impairment and those living in the same society who do not have the same physical characteristics. Under this concept the professional worker: doctor, nurse, therapist etc., and his/her working relationship with the individual who has an impairment, replicates and expresses the condition we call disablement. I believe this simplifies the parameters of disability and suggests, as I said earlier, at least one crying need for research – namely into the dialectics of the professional-client (or helper-helped) relationship, which I see as being an expression of disability.

Another area for research seemed to me to have been raised in Chapter 13 by Dr Pheasant who discussed the problems of assessing biomechanical aspects of strength and mobility. Here I was struck by the emphasis on the vast range of functioning which emerged when attempting to define and record movement such as walking. To me the graphic representation of movement presented in his figures read like a fingerprint of each individual. If there is a unique pattern of movement for each non-impaired individual how do we compare results? Do we, for example, talk of assessing fingerprints? Perhaps there is a need to rethink and research the dimensions we choose to express the uniqueness of an individual's impairment or his disabling relationships?

Of particular interest to many disabled people is a point mentioned by Dr Wolffe. He notes in Chapter 10 that in any assessment procedures great care must be taken to ensure sufficient time is allocated – the physically disabled are slower in performing physical functions, as one would expect. I would like to suggest this may be taken further. It seems to me that the problem may not just be that disabled people are slower (though this maybe the problem for most) but that this is incorporated into the individual's life style so that his or her 'sense of time' is altered. At least some disabled people may develop different body-clocks to that of the normal 24-hour day non-impaired variety and, I am suggesting, this too may become manifested in the disability relationship and perhaps, sometimes, be erroneously construed as 'slowness'.

I am reminded of a patient who was once referred to me in the psychiatric setting. The psychiatrist, knowing that I could provide behaviour therapy, felt one of his patients had a problem which would be amenable to this procedure. She was a gypsy and amongst other psychiatric problems she seemed unable to tell the time – she was late for meals, etc., and upset ward routine. The intention was that if I did not at least initiate some programme which would enable her to read the time then at least I would provide a programme utilizing conditioning procedures which would result in her responding to the time table of the ward. On interview I was struck, however, by what seemed to be her different sense of time. It was not that she could not tell the time (she was able to do this with limited success) but that she had a different attitude towards the phenomenon. Cultural differences in perception of time are, of course, not unfamiliar, but the implications of this when one lives in a society where the sense of timing is different to one's own sense did not occur to me before interviewing the gypsy. I am suggesting, here, that I know of no research which looks at the perception of

time by disabled people as a component of the disability relationship other than at the crude level of measuring how long it takes a disabled person to perform an activity.

Finally, several contributors mention psychological phenomena such as personality, attitudes and, in particular, the need to motivate disabled people. Here again, I fear these concepts may reflect the unconscious assumptions of the professional or lay worker in the field when they contemplate *their* side of the disability relationship rather than being a reflection of something existing solely within the psychology of the disabled person. The unstated assumption is that disabled people are passive and when they act they do so because they are pushed or pulled into activity. The argument seems to be something like this: 'A disabled person is seen not to be performing as well as he or she might and this is interpreted by the worker as indicating lack of motivation. Later when considering the quality of the performance the worker then sees its cause lying in lack of motivation.' What I am suggesting here is that the construction of concepts such as motivation may owe its genesis more to the society-given legitimacy of one person having 'qualified' rights of interpretation over the behaviour of another, than to existence of this abstraction within the observed disabled person. That is to say the existence of these concepts (personality, attitudes, motivation) *and* the desire to measure them may also be yet another expression of the disability relationship. A line of research could be to investigate the origins and functions of these terms in the professionalisation of disability.

### **Activity/passivity – the disability relationship**

I should now like to try to clarify what I feel are a few erroneous assumptions about the disability relationship and which I think may be quite endemic amongst professional workers. It may be, of course, that the professionalisation of workers with disabled people of necessity, in response to the needs of their professional status, involves taking on board inappropriate assumptions about disabled people. Far more likely, however, is that professional assumptions are inconsistent and often ambivalent.

Mr Green said in Chapter 20 'Man is by nature a struggler', that is, people (including those with physical impairments) are not just passive. When faced with problems they constantly search for solutions, interpretations of their situation and changes to their circumstances. The process of struggle (in Mr Green's sense) seems to me, however, prone to great ingenuity and subtlety, so much so that the way in which one person may struggle for personal solutions may manifest to another as lack of struggle and lack of motivation. I believe this particularly true in the professional setting of medicine and disability.

If I may illustrate from my experience in the psychiatric situation, like many clinical psychologists I became disillusioned with much of our intellectual, attitudinal and personality assessments carried out on patients and fed to psychiatrists for diagnostic purposes. One is persistently made aware that such assessments have little to contribute to patients' treatment and well being. Having, as a department, decided to cease these assessments, unless obviously relevant, it was an easy logical step to consider passing the new reports of our interviews and other assessments which were directly related to the patient's situation over to the patients for their opinion and discussion.

Apart from the therapeutic implications of trying to reach mutual agreement with a client about diagnosis, the nature of the problem, and so on, there was an immediate noticeable change in the relationship between clients and myself. Instead of me, the professional, being the dominant active agent the client became a participant in the professional relationship. This in turn brought into relief the continuing relationship these patients had with their psychiatrists and they raised this repeatedly in discussions. I was particularly impressed by

the great ingenuity and high degree of motivation often revealed by patients in their preparations to convey to the psychiatrist information they felt he wanted to hear including the impression of passivity – they fed him what they felt he wanted somewhat regardless of what they felt in expressing their thoughts to me or, indeed, what the psychiatrist may really have wanted to hear.

There are two points I would like to make from this example. Firstly, it seems to me a particular kind of relationship with particular unconscious assumptions underpinning it that involves personality and attitudinal assessments and that within the disability field this has something to do with the nature of the disability itself. Secondly, the example characterizes at least one important aspect of the medical model which in the prevailing dominance of the medical model in disability also characterizes the present disability relationship.

Of course, since like Mr Green I see human beings as being strugglers by nature, I do not see disabled people expressing this indefinitely in the forms previously established. About half way through the meeting, when we were feeling perhaps a little tired and having listened to some discussions which drew attention to the lack of consensus on definitions, pervasive problems in assessment and depressing problems in unemployment, Dr Wolffe seemed to echo the feelings of the meeting when he said, in a moment of passion, we must do something to solve the problems: ‘Disabled people are out there,’ pointing through the window ‘looking to us for help...’ How many questions can we ask about the assumptions contained in the quoted phrase?

For example: ‘Why are they out there and not in here attending the meeting?’ ‘Are they really looking to us for help?’ ‘If they are, in what way are they looking at us?’ Like my example of psychiatric patients, ‘is the “out there looking to us for help” perhaps simply an expression about disabled people and one which disabled people reinforce for their own unpublicly stated reasons?’

But I think it is no longer appropriate to portray disabled people quite so passively. Disabled people have always discussed amongst themselves the relevancy of professional constructions of disability and the problems that they really face. In addition, of course, disabled people often respond to the questioning of workers in the field by providing suggestions for solutions, be this a minor aid or major proposal for a social service. Sadly, professional workers all too often appropriate these ideas and present them as their own thus establishing and reinforcing the notion of passivity amongst this population group.

The growth of expertise amongst disabled people, however, has led to an increasing formalization of their views on workers in the field and their views. Of late research is being instituted by disabled people for themselves. There is a creeping awareness of the need for disabled people to define their own situation and to publish their views in their own right. At the risk of simplifying the problem the logic goes something like this:

- (1) A professional or lay worker contemplates and defines the situation of the disabled client (the current situation).
- (2) The disabled person contemplates his or her own situation and those he or she identifies with (the growth development).

An examination of the above two situations shows clearly, albeit simplified, that professional or lay research and service is dependent upon the existence of the disabled population whereas the converse is not true – research carried out by disabled people is not dependent upon professional or lay workers (although, of course, certain expertise is required). In this formulation, where the professional worker earns his livelihood from the existence of the disabled population there arises an unconscious vested interest in the maintenance of the

disability relationship. The relationship assumes passivity and there is a strong suggestion that there is a vested interest for the professional to propagate this view so that it will gain public acceptance. How much of the public awards for services to disabled people and the imperative to create qualifications in working with disabled people acts to maintain the illusion of passivity amongst disabled people should in my view prove a useful line of research.

If it is the worker in the field who is dependent then perhaps too the really passive participant in the relationship is the worker. The disabled person, in this interpretation, is the active agent reinforcing the convoluted interpretations the professional or lay worker makes of his disabled client. Of course, if this kind of mental gymnastics is really going on then it is hardly surprising clarity of thought on handicap and disability has proved so difficult! This would be equally true for both the worker and disabled client as long as they both unquestioningly accept the underlying assumptions of the prevailing disability relationship.

Disabled people who question the professional construction of their situation, however, perhaps have a greater vested interest in unscrambling the definition problem. Certainly, a growing number of disabled people are questioning the prevailing assumptions and I think it is true to say that as disillusion with the professional definition of the situation of disabled people grows so too there will be increasing reluctance to reinforce the old passive/dependent disability relationship. As disabled people increasingly research their own situations so they may become increasingly reluctant to participate in research, answer questionnaires etc. which are based upon the assumption of passivity in themselves.

At least in one instance organized disabled people have already discussed the value of preparing a questionnaire to be handed to research workers for completion, the results to be analysed by themselves and used as a basis for deciding whether to co-operate in research or not. A question of the researched researching the researchers! I can well imagine the emergence of 'new' professional researcher personality scales – e.g. the 'identifier' (with the situation of disabled people) ? 'aloofness'. Whatever the merits or demerits of this development one thing is certain – the process of self-identification with its implications for research and theory has come into its own and there is no question but that this will increase all over the world. Unless researchers and other workers in the field re-examine their traditional assumptions they will be left out in the cold with piles of unanswered questionnaires.

### **A suggested definition**

Before concluding I would like to say a few words about a possible different way of defining disability consequent upon focussing on the situation of disabled people through their eyes. An example will identify the problem. We will assume a woman has an impairment to her spinal cord resulting in lower limb paraplegia. She uses a wheelchair. She is at home, it is lunch time, there is no food in the home or anyone to provide food. She is hungry.

Given this situation she may well want to go to the shops and buy some food. She opens the front door and is stuck. There are three steps. Fortunately the milkman appears at this point and helps her in her wheelchair down the steps. She pushes her way along the pavement towards the bus-stop and has to cross a road. There is a kerb. She is stuck but fortunately a pedestrian helps her down the kerb across the road and up at the other side. She reaches the bus-stop just in time for the bus. It stops in front of her and she is stuck. The entrance platform is too high. The conductor and some kindly passengers help her into a seat and stow her folding chair on the bus. On reaching the shopping centre they help her alight, setting up

her wheelchair on the pavement. Very hungry she manages to push herself at last to the food shop and is stuck. The shopkeeper refuses to allow her entry.

She bursts into tears – she has been stuck once too often. A sympathetic passerby in a car takes our tearful wheel-chair user home and rings her doctor. On arrival the doctor asks what is the matter and, hardly surprising in the light of the day's experience, she bursts out: 'Oh, I wish I could walk'. 'There, there,' says the doctor, 'you must accept your disability' and prescribes medication to calm her down.

Not being a party to the living experience of disability the doctor focuses upon the individual and interprets her desire to walk as self-explanatory. We know, however, that if she had not been stuck at her front door, at the pavement kerb, at the entrance to the bus and denied entry into the shop (a) she would not have felt the need to walk, and (b) the doctor would not have been called into the situation. I am suggesting that the conjunction between the disabled person's expression of a desire to walk and the legitimisation of the doctor's (or other worker's) intervention is a product of the existence of environmental barriers to normal social behaviour (i.e. 'shopping'). If these barriers are seen as disabling to the person with a spinal cord impairment then the resultant client/worker relationship is a replication of the disablement relationship in a different form. What is crucial is whether the worker focuses upon the disabled individual as having the problem and accepts the language of frustration at face value or whether he or she attempts to contemplate the living reality through the eyes of the struggling active disabled person. Is the problem to be 'objectified' within a passive individual 'sufferer' or is it to be seen in the product of active social relationships (human and environmental)?

In my view it is not the fact that the person in our example cannot walk that is disabling but that society is organized for walking and not wheelchair-using individuals. Her disability is not paraplegia but steps, pavement kerbs, buses and prejudiced shopkeepers. It is the way in which society is organized that determines the disablement, or meaning, that is given to an individual with a specific impairment. In short, since my purpose in this paper is not to present a detailed analysis of possible definitions, I would epitomize disability in the statement 'Society disables people with physical impairments'. Disability, therefore, is a particular social relationship requiring for its comprehension sociological models rather than medical, paramedical, psychological etc. ones.

While the individual has an impairment, and it would be nice if this could be eliminated once this is stable, many disabled people see the problems as emanating elsewhere, outside their own bodies. Most disabled people have little problem in accepting a social definition such as: 'disability is the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities'. Such a definition assumes disabled people have normal human characteristics such as being by nature strugglers, or active, and are part of society unless deprived of participation. It implies that research into the assessment of disability may be conducted not on the disabled person but on others and upon disabling situations.

## **Conclusion**

Disability, it seems to me, is a paradoxical relationship. It implies passivity amongst people with impairments when they may be by nature active, it implies dependency upon workers in the field when those workers may be dependent upon them, it implies social isolation when they may best be considered as part of society, and so on. Dr Slattery drew our attention in Chapter 23 to his particular experience of the paradoxical relationship we call disability.

Industry, he said, must develop and incorporate new technologies to enable them to compete in the world markets. While the development and use of these technologies make employment possible for the most severely physically impaired individuals they at the same time lead to the shedding of able-bodied labour and so paradoxically make the employment of disabled people even less obtainable!

I believe this is an excellent summary of the very essence of the social nature of disability and it is *this* paradox that urgently requires research.

### **Further reading**

Finkelstein, V. (1975) Phase 2: Discovering the Person in 'Disability' and 'Rehabilitation'. *The Magic Carpet* (New Year, 1975) 37(1), 31-38

Finkelstein, V. (1975) More on Phase 2. *The Magic Carpet* (Spring, 1975) 37(2), 16-17

The Union of the Physically Impaired Against Segregation (1976). *Fundamental Principles of Disability*. (UPIAS, c/o Flat 2, St Giles Court, Dane Road, London W13)