

THE COMMONALITY OF DISABILITY *

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Introduction

How a disabled person sees her or himself may not only affect the way problems that they face are identified but also influence the way help offered by others is accepted or rejected. Seeing oneself as suffering because of an impaired body or function could lead to demands for assistance to become as normal' as possible. On the other hand, if discrimination is seen as causing the difficulties then help aimed at providing equal opportunities could be the preferred option. I-low disabled people identify themselves, then, can be very important in developing intervention strategies for services as well as helping them to help themselves. The question is, what is this identity?

The growth of new organisations of disabled people during the past two decades has been compared to the development of the black and feminist movements for civil rights (especially in the USA) (*see* Oliver, 1984; Abberley, 1986; Driedger, 1989; Morris, 1991). However, in focusing on civil rights as a common feature of race, gender and disability discrimination it may be forgotten that each form of discrimination also has its own unique characteristics.

If, for example, an operation was introduced which transformed black people into white or women into men then discrimination could no longer be based upon skin colour or gender. However, in the first place such an operation would be universally rejected by these groups. Second, in the case of race, other features such as culture would replace skin colour as the new focus for discrimination;¹ or in the case of gender, success would lead to human extinction. Regarding race and gender, therefore, physical intervention like surgery on individuals could never be a route to the end of discrimination against these groups. This argument does not seem to apply equally well to the removal of discrimination against people who have an impairment of body or function.

First, very many disabled people would welcome physical interventions which guarantee elimination of an impairment. This is surely demonstrated by the continuing attraction of rehabilitation programmes to return function; support for research into modifying multiple sclerosis, epilepsy or spinal injury, etc.; the frequency of corrective surgery (such as removal of cataracts) and use of equipment to approximate normal behaviour (such as hearing and walking aids). Even disability organisations sceptical about experiments to make disabled people 'normal' do not campaign against the prospect of eliminating impairment. Parent agitation for 'conductive education',² which aims at developing normal behaviour in children who have an impairment (cerebral palsy), has no parallel amongst other groups struggling against discrimination. It is inconceivable, for example, to imagine a similar approach being supported by black parents to make their children white or parents and the government supporting systems to make their daughters into boys. Second, interventions which eliminate impairment not only remove the focus of the discrimination but cannot be replaced with

* This paper is based upon the ideas developed in V. Finkelstein (1990) 'We' are not disabled, "you" are', in S. Gregory and G. Hartley (eds) *Constructing Deafness*, Pinter, London/The Open University, Milton Keynes.

another way of identifying the same group for continuing discrimination (as racial prejudice can shift from ethnic to cultural, religious or geographic origin).

A negative reality, negative attitudes

If people with significant hearing, visual, motor or learning impairments are disabled during their day-to-day encounter with a social and physical world designed for able-bodied living then their shared experience could lead to a common identity. This suggests that people with hearing impairments, for example, may have more in common with other disability groups than with other language-oppressed groups. This is not to deny that all oppressed groups share some common features. However, I believe disabled people's difficulties are best understood by looking at the link between body impairment and discrimination against people who have these impairments.

The reason why few individuals would willingly identify themselves as disabled until recently is not immediately obvious. Perhaps this has to do with the general confusion of disability as a synonym for physical impairment (with negative associations) and as a term for those who suffer discrimination. The universal instinct of disabled people to separate their experience of discrimination (which should be opposed) from the experience of living with a body impairment (which has to be managed) may explain the general reservation about identifying oneself with a term which confuses both states.

However, it may seem a mystery why, if most people who have bodily impairments, such as spinal injury or cerebral palsy, object to the label 'disabled', it has been so difficult to stop the use of the term or find an accepted alternative. The term, 'person with a disability', for example, not only still refers to disability but cannot be distinguished from the label 'person with an impairment'. Replacing one label with another while the day-to-day reality of disability remains unchanged seems to be an exercise in changing fashions, even adding more confusion to the relationship between impairment and disability.

All this suggests that there might be good reasons why many people remain opposed to the term 'disabled'. If despite all efforts attitudes are persistently negative, then we need to question the assumption that ignorance or misunderstanding leads to negative attitudes. On the contrary, perhaps there is some sense in negative attitudes towards disabled people because this reflects the actual negative status of disabled people in society.

Regardless of what disabled people like to think about themselves, then, as long as their unfavourable situation continues people will be likely to see disability in a negative light. One set of facts immediately stands out when we look at the situation of disabled people. Government statistics (see, for example, Office of Population Censuses and Surveys, 1988), independent research projects (Barnes, 1991) and personal experiences,³ show that on nearly every indicator of participation in mainstream life disabled people come out extremely badly; for example on employment statistics, income levels, suitable housing and access to public transport, buildings, information (newspapers, radio and television) and leisure facilities. Being disabled, then, has clear negative implications.

The marginalisation of disabled people

If we look at history it should be possible to identify a process which led to the isolation of people with physical and mental impairments from their communities and created their present negative status.

Contemporary literature over the centuries shows that although people with physical and mental impairments have always had a low status in society they have, nevertheless, also

lived in periods when they are publicly visible in their communities (as is still the case in many third world countries). The 'cripple' begging in the street or the deaf person working in some menial job were still members of a community. The public disappearance of cripples was a lengthy process which involved increasing acceptance of 'normality' as a criterion for social integration.

A case in point is the way that signing as a means of communication for deaf people was suppressed. That this may have been suddenly opposed may be historically true (see Ladd, 1991), but how are we to explain this change in attitude? In other words, despite their wishes what conditions led to the disablement of people who use signing as their means of communication? I believe that the meaning of disability is determined by the way our society is organised.⁴ In this respect the decision to oppress sign language would not only be socially determined but also the meaning of deafness to the general public. If the social situation of deaf people is disabling (because auditory methods dominate all communication) then deafness will be considered as a disability regardless of what deaf people want. The only way to change this interpretation would be to remove the barriers to non-auditory communication.

One view, first raised in Finkelstein (1980), is that the predominant factor contributing to the disablement of different groups is the way in which people can participate in the creation of social wealth. For example, at a time when small-scale manufacture was carried out in the individual home, or when transport was individualised with the horse and cart, or when products were exchanged in small stalls in the market-place, then there might have been some scope for these activities to be carried out by people of different shapes and sizes. Being deaf or having a club foot and working a hand loom at home could be a viable means of livelihood.

However, the invention of the steam engine led to the introduction of more efficient machinery than, say, the home-based hand loom. But the new machinery of the industrial revolution had to be worked not by a specific individual but by an unknown 'average' person who might be hired of the street (that is, the 'hands'). People who deviated from this 'norm' were likely to become unemployed as more and more machinery was introduced into the productive processes. Operating increasingly sophisticated machinery also meant that potential workers had to be able to follow instructions designed for 'normal' workers (that is, oral and sometimes complicated written instructions).

Under these conditions it seems clear that the increasing dominance of large-scale manufacture created conditions which progressively raised the importance of 'normality' as well as the importance of designing machinery, buildings and transport systems to places of employment for normal people. Being normal, then, became a dominant criterion for employment in industrial societies and this would have encouraged the suppression of non-normal behaviour, such as the use of signing for communication, or the exclusion of those who could not see or walk.

Where this led to certain groups of people being marginalised from productive life, then they would have had no alternative except to beg and rely on charity.

Managing the marginalised

Undoubtedly this led to large numbers of beggars and made a policy for their removal a necessity. Once the process of removing these unemployed from the community was well under way (into alms houses and later into large institutions), then there must have been pressure to provide food and shelter only for those who were regarded as unable to work because of impairment.

From this perspective it became necessary to separate the unemployed into two categories: the infirm and the indolent (thieves, vagabonds, the so-called lazy, etc.). This need for classification would have enabled diagnostic experts

(doctors) to secure a special role in relation to the infirm. I believe that doctors taking on this administrative task marked the beginning of classifying and interpreting disability in medical terms. Once disabled people are defined as unemployable it seems logical for the medical experts to concentrate attention on ways of making them 'normal', or as normal as possible. If disabled people could be rehabilitated and work machinery designed for normal people then they might cease being dependent upon charity and state handouts. This approach would have encouraged the growth of different professional interventions and the provision of specialist aids for different disability groups. To facilitate this, clearer classification would be needed to separate people who are mentally ill, blind, deaf, or have learning difficulties, etc. By the middle of the twentieth century all disabled people were being routinely classified and registered by many different agencies according to medically defined categories.

Once treatments (such as physiotherapy), special services (such as provision of hearing aids) and specific benefits (such as mobility allowance) multiplied, the need to sharpen boundaries between categories of 'disability' became increasingly important and in the 1970s and 1980s there was a rapid increase in disability scales and measures. Disabled people, of course, played very little part in this process (although some organisations campaigning for financial benefits, such as the Disablement Income Group, needed to provide their own categories of people who would be eligible for the benefits that they were seeking).

Defying the label, denying the reality?

Regardless of personal wishes, therefore, being labelled as disabled is a fact of life for all disabled people in the contemporary world. As long as there is no possibility of gaining access to services or social and welfare benefits without surrendering to the label 'disabled' there will be no possibility of maintaining that an individual or group is not disabled. The use of equipment such as wheelchairs, or forms of communication such as Braille and signing, not used by 'normal' people, only confirms the user as a disabled person.

In these circumstances, if being called disabled is thought to inhibit employment prospects and a better social status, there could be an incentive to distance possession of the particular condition from those thought to be lower down the scale. This, it is falsely believed, frees the individual, or group, to consider themselves as only a variation in the pattern of normality while the others, lower down the scale, can be regarded as really disabled. For example, people with spinal injuries may see themselves as normal (restricted only by barriers which limit wheelchair mobility — that is, they are mobility oppressed) whilst those with learning difficulties are regarded as 'really' disabled. Similarly, people with hearing impairments may think of themselves as normal (restricted only by barriers to British Sign Language as a form of communication — that is, they are language-oppressed) whilst those with a spinal injury are regarded as 'really' disabled!

Assumed levels of employability separate disabled people into different levels of dependency, and this, in turn, can lead to different types of services and provisions. At the bottom, those regarded as hopelessly unemployable are offered places in residential homes where they can have total care, whereas those who can work may have access to special equipment and adaptations funded by the state. Ranking disabled people according to degree of employability provides another context for disabled people to constantly fear that they may become associated with those that they see as less employable and more dependent. By trying to distance themselves from groups that they perceive as more disabled than themselves they

can hope to maintain their claim to economic independence and an acceptable status within the community.

Subjective and objective factors in the lives of disabled people, then, constantly interact and encourage them to distance themselves from each other, denying that they are disabled while defining others with this label. When one group of people with a particular form of impairment (such as hearing impairment) see themselves as fitting into the normal range (for example their language is oppressed but they are not disabled) while at the same time they view people who have different impairments as disabled, they are attributing medical labels to others in exactly the same way that they reject such labels for themselves!

Reclaiming control: self-empowerment

I believe that despite the preference of people with physical or mental impairments not to see themselves as disabled current approaches to services present the general public with a powerful image of disabled people as a unified, dependent population. These approaches can be regarded as the outcome of the administrative role given to medical practitioners in the care of disabled people. The growth of specialist professions and their publicly visible role as gate-keepers to medical, social and welfare services provides an effective reinforcement to the view that disability is a medical problem. The fact that being 'normal' is still very important for employment, promotion, and gaining an independent livelihood, means that the role of medicine in the lives of disabled people remains extremely significant.

Publicity for rehabilitation aimed at normalising disabled people's behaviour or appearance (such as surgery to enable children with cerebral palsy to walk, or electronic implants to enable hearing in people with auditory impairments) confirm the public's attachment to the medical interpretation of disabled people's needs. The medical approach towards disabled people has been much discussed and criticized (see, for example, Oliver, 1981; Brisenden, 1986; British Psychological Society, 1989; Abberley, 1991) but it still dominates current legislation and provides the main criteria for defining

categories of people who shall have access to services and benefits. The overriding political feature of interventions administered by medical practitioners is that it brings all disability groups together under a single medical interpretation of the cause behind their marginalised position in society (the medical model of disability).

Criticism of the medical model has led to changes, and there are increasing signs that services are moving away from medical control provided by the health service to social and welfare interventions provided in community services. The problem is, however, that this shift does not necessarily result in disabled people having greater control over their lives. On the contrary, community-based service providers generally have a wider perspective than their medical colleagues in identifying areas of disabled people's lives for their professional assessments and interventions. This may leave very little for disabled people to do without feeling that an expert is waiting in the background to intervene. The community worker is there to provide expert assessments and advice on nearly everything, from the architecture of the home, the whole range of equipment that all people need for modern living, to advice and counselling for intimate personal and sexual problems.

In this respect experts are often encouraged to see the lives of disabled people in terms of problems to be solved and their role as providing solutions. Nationally, then, the existence of large and expensive social and welfare services provides ample evidence that a characteristic of all disabled groups is that they face a series of problems which they cannot solve on their own and which the state has had to administer through the provision of specialised services.

From this point of view disabled people are socially dysfunctional (in Miller and Gwynne's words they are 'socially dead'; Miller and Gwynne, 1972; *see* also Finkelstein, 1991). This could be called the administrative model of service intervention. In the first instance the medical profession was given this role when they were unable to 'cure' an individual's impairment. The shift towards community-based services is transferring the duty to other professionals without, however, changing the basic approach to intervening in the lives of disabled people.

It is this administrative approach to disability that draws different groups of disabled people together in the assessment forms for problem-solving and service provision. From this point of view disabled people can be identified as a distinct social group (with several disability sub-groups). Modern disability movements which bring together groups of disabled people and encourage a common identity not only reflect the growth of a united front against medical and administrative dominance but also represent an historical leap in redefining disability in positive terms. Those who enact helping interventions need to recognise that the changing meaning of disability provides a new context for the construction of services with disabled people on a quite different, dynamic understanding of disability.

Notes

- 1 See paper 2.4, by O. Stuart, in this Reader, where this interpretation is first applied to the discrimination faced by disabled people from ethnic minorities.
- 2 For a discussion on this approach see paper 3.5, by M. Oliver, in this Reader, and the rejoinder by V. Beardshaw. See also Finkelstein (1990).
- 3 The journals of local disability associations regularly contain personal accounts of difficulties in managing to negotiate the immediate environment, for example on inadequate access to local public transport.
- 4 Oliver has written extensively on this issue; see, for example, Oliver (1983).

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