

Independent Living and the Medical Model of Disability

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Our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of 'experts', particularly medical experts.

These reproduce the myths of disability through books, articles, lectures and other forms of sooth-saying and oracle, whilst also having the good fortune to receive a salary for their efforts. It is not, of course, in dispute that they deal with the facts -the question is rather one of whether these facts can be adequately interpreted from a strictly medical point of view.

Is the perspective of medicine historically blinkered, such that 'the facts' are inevitably sucked into a mode of interpretation that has been pre- determined beforehand? Are these 'facts' simply processed in such a way that there is necessarily built upon them an image of the disabled person as inadequate?

Presumably it is possible, under certain conditions, to isolate a set of 'facts', in the form of a list of general physical or intellectual characteristics, that apply to each form of disability. But the use of these is limited as there cannot be a formula derived from them that will cope with the particular needs of each individual. Indeed, taken alone, the 'facts' may lead only to distortion and misunderstanding and to a view of disabled people as a category of rejects, as people flawed in some aspect of their humanity.

The medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual.

In order to understand disability as an experience, as a lived thing, we need much more than the medical 'facts', however necessary these are in determining medication. The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to be disabled.

As well as the 'facts', therefore, we need to build up a picture of what it is like to be a disabled person in a world run by non-disabled people. This involves treating the experiences and opinions of people with disabilities as valid and important; more than this, they must be nurtured and given an overriding

significance, in order that they begin to outweigh the detached observations of the medical 'expert', which have invested in them the power of history.

Our experiences must be expressed in our words and integrated in the consciousness of mainstream society, and this goes against the accumulated sediment of a social world that is steeped in the medical model of disability.

It is vital that we insist on the right to describe our lives, our disabilities, and that we appropriate the space and proper occasions to do so. After all, the way something is presented will condition to a great extent the way it is received, as any newspaper or television editor will tell you. If the experience of disability is always presented in the context of the medical implications it is supposed to have, it will always be seen as largely a matter of a particular set of physical or intellectual dysfunctions and little else. In this way the myth is perpetuated that disabled people require medical supervision as a permanent factor in their lives. As in society generally, the language used and the situation in which it is expressed will determine the message that goes out to those listening.

There are plenty of colloquialisms that indicate the damage that can be done through inappropriate terminology. Disabled people are seen as weak, pathetic and in need of sympathy when they are referred to as 'cripples'. A person with cerebral palsy, when referred to as a 'spastic', has to suffer the indignity of being equated with a raving, dribbling, idiot- these are the facts beyond the medical 'facts'. What we have to get to, instead of this, is the real person inside the image of disability.

To begin with, we are not 'the disabled'. We are disabled people, or even people with disabilities.

It is important that we do not allow ourselves to be dismissed as if we all come under this one great metaphysical category 'the disabled'. The effect of this is a depersonalization, a sweeping dismissal of our individuality, and a denial of our right to be seen as people with our own uniqueness, rather than as the anonymous constituents of a category or group.

These words that lump us all together - 'the disabled', 'spina bifida', 'tetraplegic', 'muscular dystrophy', - are nothing more than terminological rubbish bins into which all the important things about us as people get thrown away. Similarly, as part of this general burial of our personality, we must note the in which the form of presentation of a disabled person's experience can be prejudicial to whether that experience is understood. It can pre-determine the image of a disabled person's life that comes over, whilst appearing on the surface to be an objective attempt at allowing us to speak for ourselves.

Every year at a major medical faculty in Southern England, a doctor interviews a disabled patient in a lecture theatre in front of over a hundred medical students,

as part of a course on disability. The point of the exercise is to introduce the students to the problems that disabled people face in society, and to get an authentic point of view from a 'real' disabled person who can recount how a life has been affected by disability. But is an interview with a member of the medical profession – particularly in front of such a large audience - likely to be the best forum for reaching the nuances and particularities of an individual life?

And does not the method of enquiry itself reinforce the established view that disabled people are 'passive' and non-disabled people 'active'? Does it not also characterize a disabled person's life as legitimately open to prying questions in front of an inquisitive public?

It all seems to rest upon the mistaken premise that you can somehow learn about a person's life by asking them questions about the nature of their disability -an idea that assumes the person to be defined by the disability.

The reality of the matter is that under the guise of objective scientific enquiry a particular image of disabled people is being fostered in the minds of the audience, and it is an image full of negative implications which are in themselves disabling.

I have a fantasy that in some future world people with disabilities will be able to insist on the right to interrogate doctors, rather than be interrogated by them. In this fantasy, a doctor is placed on stage in front of a large audience of people with disabilities, in order that we may come to understand the stigma of a career in medicine, and the effect this may have on family and friends.

Someone would then ask the doctor a series of searching questions, such as: 'When did your profession begin? Was it the result of an accident, or is it a deteriorating condition?' I suspect that we would learn very little about the individual beneath the white coat, but the feeling of power might prove too irresistible to be ignored.

The word 'disabled' is used as a blanket term to cover a large number of people who have nothing in common with each other, except that they do not function in exactly the same way as those people who are called 'normal'. Consequently, this large number of people are considered 'abnormal'. We are seen as 'abnormal' because we are different; we are problem people, lacking the equipment for social integration. But the truth is, like everybody else, we have a range of things we can and cannot do, a range of abilities both mental and physical that are unique to us as individuals. The only" difference between us and other people is that we are viewed through spectacles that only focus on our inabilities, and which suffer an automatic blindness - a sort of medicalized social reflex -regarding our abilities.

The dustbin definition of us as 'the disabled' is a way of looking at us not as people with different abilities, and consequently different needs, but as non-people with non-abilities; not as people who can construct a life out of our different abilities, but as helpless individuals who have to be forced into a life that is constructed for them.

We are the outcasts in a society that demands conformity to a mythologized physical norm, the pursuit of which leads to neurosis and is the cause of much guilt and suffering.

The impossible demands made on us by this norm, against which we are measured and found to be inadequate, are at the root of our oppression.

We have been entirely defined by what are seen as our inabilities and are given the blanket label of 'the disabled'; a label which is pregnant with hidden ideological overtones. It teaches us a conditioned uselessness, which is not based upon our actual physical or intellectual capacities, but upon the desire to make us believe that we are a drain upon society's resources. It teaches us to be passive, to live up to the image of ourselves as objects of charity that we should be grateful to receive, and to ignore the possibility that we may be active people who have something to contribute to society.

This labelling process leads to us being excluded from all spheres of social life, and allows people to treat us either as morons or as creatures from another planet. Yet it is in fact the posture of society at large that constitutes the most disabling part of being disabled, not the physical effects of whatever condition one happens to have, unless it leaves the individual utterly bed-ridden or completely fatigued.

On the whole, it is the organization of society, its material construction and the attitudes of individuals within it, that results in certain people being disabled.

We are only people with different abilities and requirements, yet we are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dextrous.

If society was organized on a more equitable basis, many of the problems associated with not being physically 'perfect' (as if such a concept had any logical basis), would physically disappear. The most obvious example of this has paradoxically been most clearly ignored, despite half-hearted attempts to rectify the situation. I refer to the problem of access to buildings and facilities in the community, and to the callous disregard with which our needs are ignored despite the efforts of sundry committees, working parties and other bodies on our behalf.

We are disabled by buildings that are not designed to admit us, and this in turn leads to a whole range of further disablements regarding our education, our chances of gaining employment, our social lives, and so on. The disablement lies in the construction of society, not in the physical condition of the individual.

However, this argument is usually rejected, precisely because to accept it involves recognizing the extent to which we are not merely unfortunate, but are directly oppressed by a hostile social environment.

The question of definition bears very directly on the outlook of the medical profession, which has exhibited an unwillingness to revise the way that it views people with disabilities. The problem, from our point of view, is that medical people tend to see all difficulties solely from the perspective of proposed treatments for a 'patient', without recognizing that the individual has to weigh up whether this treatment fits into the overall economy of their life.

In the past especially, doctors have been too willing to suggest medical treatment and hospitalization, even when this would not necessarily improve the quality of life for the person concerned.

Indeed, questions about the quality of life have sometimes been portrayed as something of an intrusion upon the purely medical equation. This has occurred due to a failure of imagination, the result of the medical profession's participation in the construction of a definition of disability which is partial and limited. This definition has portrayed disability as almost entirely a medical problem, and it has led to a situation where doctors and others are trapped in their responses by a definition of their own making.

They cannot respond in ways that go outside the parameters of a view of disabled people which they themselves have created. They are stuck within the medical model of disability.

The limited parameters of this model have been passed on to other professionals and to people with disabilities themselves, leading to unimaginative responses by service providers, and to low expectations on behalf of themselves by those who have a disability. This depressing situation may, to some extent, be changing, but disabled people still suffer from being viewed and defined within this medical model, with its implication that someone will - and should - always be in and out of hospital.

This way of looking at things ignores the sociological and psychological aspects of disability. It ignores the fact that frequent hospitalization and medical treatment is in itself one of the most disabling factors about being disabled. We should instead look at life as a whole, and allow people with disabilities to take decisions for themselves based on many other factors as well as medical ones.

We have to look at a person's independence and ask how this can be assisted and promoted without taking the right of control away from the individual. The individual should always be allowed to determine how a specific medical suggestion fits into the overall medical economy of their life.

In order to break down this disabling definition of disability as exclusively a medical problem, with medical and paramedical solutions (which in most cases means no 'solution'), we must distinguish between a disability and a disease, for there is frequently a confusion of the two. Whereas a disease has a demonstrable physical manifestation (with the exception of the controversial area of mental illness), a disability is by no means this sort of tangible thing.

It results from the things one is not able to do because of the organization of the world around you; its causes are predominantly rooted in external social factors. It is usually entirely inappropriate to see someone with a disability as a person who 'suffers' from a disease, because this will not contribute to an understanding of the life they lead.

It may well constrict the possibilities of such a life by drawing the individual back within the medical model and its debilitating emphasis on physical limitations and low expectations.

Many disabilities are clearly not diseases, because they result from traumatic accidents, but even in cases where a disease can be named as the cause of certain physical characteristics it is not helpful to see the individual as a 'diseased' person.

It is certainly not appropriate in cases where a disease is congenital and has existed in a factor in someone's life since the day they were born. In this situation a person is simply leading a life which is in some ways different to the expected norm. To look at this person as having a disease is to ignore the fact that the disability has always been integrated within all aspects of their life, and does not represent a change from some 'norm' which was never applicable to them. The disability is simply part of being the person they are, in the context of the social world they live in.

Indeed, there is literally no case in which a disabled person should be seen as 'diseased', because no disease related to disability (or anything else for that matter) extends so completely into a person's life as to define that person.

To meet a disabled person and respond by asking them what 'disease' they have, is at best irrelevant, and at worst is a way of enforcing your view of us as abnormal, a different and unfortunate species of being. It is far better to respond to someone not as if the disease defines the person, but as if the person is concerned with leading a full and interesting life.

In the independent living movement we reject these definitions that limit and control us, because they do not describe our aspirations in society. In fact, the medical definition or model has to a great extent contributed to placing us outside society, in special institutions and ghettos. We describe a place in society, participating as equal members with something to say and a life to lead; we are demanding the right to take the same risks and seek the same rewards. Society disables us by taking away our right to take decisions on our own behalf, and therefore the equality we are demanding is rooted in the concept of control; it stems from our desire to be individuals who can choose for themselves.

People with disabilities are increasingly beginning to fight against structures that deprive us of control of, and responsibility for, our- selves, and hence leave us with no real chance of participation in society.

We are the victims of a vicious circle, for the control that is denied the disabled individual by the medical profession, social services, relatives, etc., conditions that individual to accept a dependent status in which their life only takes place by proxy, resulting in them being unable to visualize independent ways of living.

The control that we demand over our own lives is one that accepts that we are as irresponsible as everybody else and that we may not always do the right thing from a medical point of view. This is what I mean by the right to take risks. If we are to be treated as individuals who are due the same respect as other people, then we must be allowed to choose a way of living that confronts all the options and risks throughout life that are inherent to living in, rather than outside, society. We believe fundamentally that all individuals have the right to live independently in the community regardless of their disability.

But it is important to note the sense in which we use the term "independence," because it is crucial to everything we are saying. We do not use the term 'independent' to mean someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led. It cannot be applied to someone living in an institutional setting, therefore, because the routine of their life will be pre-determined, to a greater or lesser extent, by the needs of the professionals in charge of the institution.

However, it can be applied to the most severely disabled person who lives in the community and organizes all the help or 'care' they need as part of a freely chosen lifestyle.

The most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine. The degree of disability does not determine the amount of independence achieved.

We believe that the choice of independent living is not a privilege conferred on us by a generous society, but is the right of all individuals, regardless of disability, to

live in the community. We see it as a right that has to be restored to us rather than a freely given gift.

Those people with disabilities who have achieved it in our society today, usually have done so through a process of struggle that continues day in day out. Yet the benefits far outweigh the disadvantages of the struggle, and the struggle becomes less difficult as more and more people with disabilities assert their right to live independently.