THE PROCESS OF BEING DISABLED

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Explored here is the complex interplay of ideas and attitudes that reinforce the roles of 'helper' on the able-bodied, and 'helped' on those people with a disability. What happens to those with disabilities who try to be assertive is discussed, as are the implications for change this demands of those who are able-bodied.

THERE IS a pressing responsibility placed upon us all to ensure that disabled people are helped out of the 'sub-caste' that our body shape or condition frequently relegates us to. Disabled people find themselves very much at the 'bottom of the heap' materially (The Disability Alliance, 1987). The great majority have little opportunity to help themselves out of this situation. Almost all forms of power are denied us. We are kept out of employment and excluded from much of the built environment. Even the political parties, who you would expect to court such a large segment of the population, have no coherent and meaningful policies in relation to disabled people's rights. In fact, disabled people are so badly discriminated against that many of us remain unaware and uninformed of our situation. It is essential therefore, that all involved with disabled people provide appropriately sensitive contact, which at least gives us the chance to begin to focus creatively on the unnecessary injustices we have to endure.

Unfortunately, discrimination is so 'built into' our society and established in the 'norms' of even the ways we interact with disabled people that we are all very likely to be the unwitting 'agents of suppression'. This may sound a mite dramatic, but on close examination does seem to be true. It is us who, whether we like it or not, are pushed towards keeping disabled people 'out of sight, out of mind and out of money'. Able-bodiedism is a way of describing the attitudes and actions that result, in disabled people being 'kept in our place', treated as less than human and largely deprived of the opportunities to do anything about this. If disabled people are not being consulted with in a non-disabling way and their ideas are not incorporated into thinking, then it is safe to assume that able-bodiedism is in operation.

It must be said, despite many people's discomfort, that able-bodiedist attitudes, policies, practices and procedures dominate the social, health and education services to an unacceptable extent. It may appear unkind to those involved in the helping services that they should be criticised when the rest of society seems to shun any meaningful contact with disabled people. We are, in fact, very grateful for both personal and professional interest, support and help. But we ask for more, especially of the professional, who is paid by us all not to dispense 'good work' (whoever may define that), but to provide a service that is actually helpful psychologically, socially and physically, in the long as well as the short term (Marinelli and Del Orto, 1984).

Some disabled people are developing a critique of society that will mean important changes, both in the way those serious about equality for disabled people think and feel and the way society organises itself. All concerned with disabled people can provide us with the opportunity and encouragement to take part in this process. In doing so, they will help many disabled people climb out of the poverty,
ignominy and associated psychological states that characterise the great majority of disabled people's lives at present (Marinelli and Del Orto, 1984). The social milieu created by important people in a disabled person's life has a very powerful effect; perhaps empowering enough even to help us resist the massive pressures brought to bear by the way our able-bodiedist society organises itself.

A brief outline of the process of discrimination/disablement experienced by disabled people will, I hope, help people recognise their part in it and change their ways. It is based upon my own experience of disability, that of my colleagues who also work for 'Phalanx: Herts Coalition Of Disabled People', that of the disabled people I have been in contact with as their social worker and community worker and who have participated in discussion groups I've co-facilitated.

I do not wish to fall into the able-bodiedist trap of stereotyping people. Each and everyone's experience is different. This is merely an attempt to draw together disparate strands of experience into a description which may begin to explain the process of being disabled for those who are not.

The process I attempt to explain relates specifically to those with a late onset' accident, illness or condition. However, the basic process is applicable to those born with a body shape or condition different to the norm. By and large children grow up in an able-bodiedist social, psychological and physical environment. This imposes able-bodiedest values despite their incongruity with the disabled child's experience. It is later, when the child/young person with a body shape or condition different to the norm, comes to challenge important adults attitudes that their own able-bodiedism is addressed. Only then does the process of being disabled begin to be made conscious.

i. The able-bodied person experiences the onset of a permanent physical condition or body configuration different to the norm. The previously unchallenged, discriminatory values of that person indicate they are now 'inferior' to that which they used to be. This feeling is based upon the sensible realisation that the world, once so easily traversed, is now a 'minefield' of obstacles. The person, once able to exist on a relatively self-sufficient basis, is no longer able to do so without assistance. Thus is the person handicapped.

ii. The newly handicapped person quickly develops a sense of sadness and/or anger about, amongst other things, the hostile built environment that surrounds them. It quickly becomes apparent that it could facilitate different body shapes but doesn't. Emotional reactions are fuelled by the realisation that the attitudes of those who paid for the environment to be built are not just uninformed of this fact. They are also frequently not willing to be informed by those with the experience needed to help them (i.e. disabled people!). Even more galling is that even those few who are informed are unwilling to pay for appropriate adaptations.

This is how the person first becomes aware of being disabled/discriminated against. And thus are their emotional reactions to this physical representation of discrimination first 'wound up' by having their experience ignored or treated as worthless.
iii. The sense of anger and/or sadness is made more acute by able-bodiedist people acting to take personal responsibility away from the disabled person. This action can be characterised as doing things for the disabled person without prior consultation. It is likely to be the first inter-personal experience of able-bodiedism. Understandably, the easiest way to treat a newly disabled person (who is probably still ill) is to do everything for them. This can be rewarding in the short term for both the carer and the cared for, but is a short term necessity which can quickly become a longer term, very destructive habit.

iv. The sense of anger and/or sadness is fuelled once again when the disabled person is not allowed to ‘take risks’ and fail or succeed as the case may be. It is often the anxiety of carers, family, friends etc. that create a tense environment which restricts the efforts of the disabled person to explore the limits of their shape or condition and do what they are capable of. This form of subtle able-bodiedism restricts self-determination and self-reliance considerably. In some instances, this goes as ordering disabled people not to attempt tasks or actually stopping them physically.

v. Family, friends, professional carers/facilitators etc. find it all too easy to ‘key into’ the disabled person’s sad reactions to disability. Attention and physical contact are frequently given in response to sad reactions. On the other hand, angry reactions are punished by withdrawal of attention, physical contact and in some instances even services are withheld or withdrawn. In this way disabled people are ‘pushed towards’ sad self-pity. Angry feelings provide the basic motivation to begin to do something about being disabled. It is extremely disabling to be ‘steered away’ from anger by the ‘kindness’ of those who do not recognise the need to pay attention to, value and accept the legitimacy of these feelings in relation to being disabled.

vi. Even ordinary conversation about the experience of being disabled places ‘distance’ between the disabled person and his/her able-bodiedist contacts. Attempts to be assertive by disabled people are fraught with difficulty. When a disabled person does enter into assertive conversation about their experience in a way which does not ‘gloss over’ being disabled, the response of able-bodiedist people is frequently more emotional than normal. In this situation it is difficult to remain calm and in control. But even if a disabled person manages to remain assertive, able-bodiedist people’s perceptions, because they are being challenged to look at their own values in the light of the very different experiences of disabled people, will often indicate that the disabled person is ‘over the top’ or ‘has a chip on their shoulder’. This perception is likely to push a disabled person towards being overly passive in group situations, unassertive and thus denied the ordinary opportunities to bring their experience out into the open.

It is not uncommon for an assertive disabled person’s perspective to be denied completely. This can easily lead to a raising of the temperature until conversation becomes an aggressive stand off. The disabled person is either forced to give up the argument (once again learning to become passive?), or be branded as overly aggressive and either ‘mad or bad’ (or both) for taking issue against the (able-bodiedist!) majority.

Being disabled by the environment and the attitudes of others is a
cyclical process. 'Help' given leads to a lack of self-confidence in one's own abilities. Lack of confidence leads to 'anxiety' about performing tasks and 'depression' at not succeeding where previously one had. This leads to lack of motivation to attempt tasks. Not attempting tasks elicits help from others. This vicious circle can and must be broken in order that a disabled person has the appropriate mental state to keep participating in life fully. The conditions necessary to facilitate the breaking of this circle are the responsibility of people surrounding the disabled person. Without their help, a disabled person will find themselves 'fighting' not just a hostile physical and social environment, but also a subtly undermining, very powerful psychological milieu out of which there is no escape for any but the very strong of personality.

It is the suppression of anger which keeps this 'vicious circle' functioning. Angry responses to being disabled enable the victim to begin to blame others for their 'discriminated against' situation and develop the motivation to formulate ways of changing the social policy, societal norms, personal values etc. that foster discrimination.

Thus the disabled person needs to enter into creative dialogue (or assertive non-submission/challenging behaviour if blocked) with those around them. For those who wish to help disabled people do something about being treated as inferior beings, it is necessary that they value assertive and sometimes justifiably angry perspectives from disabled people as much as they value their own, probably less discriminated against, perspective. In this way the disabled person is afforded the equality that is everyone's right.

Many would agree that the helping services seem to reward disabled people's sad reactions with their time, energy and resources. Those who are assertive of their needs are often forced, because of the way services are provided, to become angry. This sometimes results in total exclusion from services. It seems to me that if the providers of services are to act in a non-disabling fashion then all the ways of interacting noted above need to be avoided. But most importantly, disabled people's anger must be understood, valued and 'rewarded' much more. Society does discriminate badly at institutional and personal levels. The helping services are society's 'front line' and are just as discriminatory as anybody else. Disabled people can be helped to do something about this discrimination at an inter-personal level even if avenues in all other directions appear closed.

However, one may wish to go further and act in a reparative, anti-, rather than non-disabling, therapeutic fashion. In this case, helping to harness anger to build motivation to address being disabled becomes a necessity. It is a serious contention that a great majority of the psychological states disabled people suffer from are the product of being discriminated against and feeling inadequate, disillusioned and unable to do anything about this (Marinelli and Del Orto, 1984)

Many disabled people, whom the helping services have regular contact with have very low self-esteem. Their own able-bodiedist values 'eat away' at their heart and mind. This makes self re-evaluation absolutely necessary. Without help and support from other disabled people and/or counsellors, many will find this impossible. The disabling nature of our society is so overpowering that many 'go under' and internalise their discriminated against state. In fact,
the great majority of disabled social work users I have talked to about such subjects tell me that suicide was a very serious consideration during certain periods of their lives. It seems that without the opportunity to re-evaluate via consistently non-disabling interaction and/or counselling and/or self-help, only the very strong or the very lucky will survive relatively 'intact'.

Meanwhile, for the great majority of the victims of the process of being disabled, depression, anxiety, boredom, loneliness, anomie, alienation and a whole range of other self-destructive feelings characterise existence. Dependence, unemployment, isolation, segregation, relative poverty, ignominy and a whole range of other socially unacceptable states are the cause of these feelings. It is little wonder that self-deprecation/loathing results when even those supposedly caring for disabled people are so often unwitting disablers. In order that many disabled people can begin to 'climb out' of a frame of mind imposed upon us by the attitudes and actions of others and the way our society structures itself, it is important that we all try to act in a non- or anti-disabling manner. Disabled people will then have a slight chance of focusing on that which frequently keeps us not even on the sidelines of society. Not even back in the changing rooms. But still struggling to get into society's non-adapted loo 'before we find we can't get on the team or the supporters' coach.

References

The Disability Alliance (1987) Poverty and Disability: Breaking the Link.