

**(From 'Disabled We Stand' (1981) Sutherland, A. T., London: Souvenir Press).**

Throughout this book I shall be using the phrase 'people with disabilities' rather than talking about 'The Disabled'. That is a phrase which many people with disabilities, including myself, find extremely objectionable, because it both depersonalises us and writes us off as individuals by implying that our disabilities are our identity.

But I have a more specific reason for avoiding the term in this context; it provides a very poor basis for any serious discussion of disablement, because it evokes a very well established set of assumptions and stereotypes. The Disabled are generally understood to be a small, clearly defined section of society, quite distinct from the public at large - poor dependent creatures, immediately recognisable as physically different from normal people.

Specifically, the term 'The Disabled' is applied to people with visible physical disabilities, particularly those causing mobility difficulties. Often, indeed, the term 'Disabled' refers specifically to people in wheelchairs, as in the case of such phrases as 'Disabled Toilets' (an ambiguous term, but not always an inappropriate one; when a supposedly wheelchair-accessible toilet is placed at the bottom of a flight of stairs the description becomes exceedingly apt.

Such aids as crutches, wheelchairs and white sticks act as the badges of office of The Disabled. It is important to realise that a person in a wheelchair is likely to be classified as one of The Disabled because she is in a wheelchair, rather than being seen as being in a wheelchair because she has a disability. Which perhaps explains why, when Franklin D. Roosevelt - a man who made no secret of being in a wheelchair as a result of polio and made frequent radio appeals supporting the 'March of Dimes' appeal for money for research into polio - appeared on television, his wheelchair was carefully not shown. While it was allowable for the President of the United States to have a disability, and even to be known to have a disability, it was apparently not acceptable for the American public to be shown the visible symbol of that disability.

But the major defining characteristic of The Disabled seems to be pitiableness. Thus, deaf people are not included in this group, because they are commonly regarded, by people who have little knowledge of the reality of deafness, not as pitiful, but as comic, a standard part of every hack joke-writer's repertoire of stereotype characters, along with mothers-in-law, Pakistanis, stupid Irishmen and

naive newlyweds. And laughter plays little part in the warm glow of charitable contempt that comes from dropping money in the collecting-box.

Pitiableness is an extremely subjective criterion, as is repulsiveness, with which it is closely allied. The common concept of The Disabled has nothing at all to do with the realities of disablement: all that is being measured is the reaction of other, non-Disabled, people. Because I, as an epileptic, am visually `normal', except when I'm tactless enough to have a fit, I don't cause such reactions; people find me no more uncomfortable to be around than any other loud-mouthed, scruffy, dirty-finger-nailed, impoverished freelance writer. As a result, I find that when I talk about myself as having a disability, I am sometimes flatly contradicted. What I find particularly offensive about this is that the statement `But you're not disabled!' is often assumed to be some kind of compliment. Compliments like that I can do without; it is for people with disabilities to decide how we choose to define ourselves, and few of us choose to do so according to the prejudices of people who consider themselves able bodied.

It does not take much thought to see that the concept of disability that I have just outlined provides an extremely inadequate definition of what constitutes disablement. Quite apart from the fact that it carries with it a host of oppressively patronising assumptions about what people with disabilities are like, it recognises only a comparatively small group of people with disabilities, leaving out such disabilities as deafness, chronic illness, epilepsy and the whole range of non-visible disabilities, speech disorders and partial sightedness. I'm not certain that it even covers blindness; it seems to me that `The Blind' are seen as a parallel, but separate group to `The Disabled'. If so, the difference probably lies in the fear that many able bodied people have of blindness as something they can imagine happening to them, which is not an attitude they have towards, for example, cerebral palsy or polio.

Somewhat fuller definitions of disability are used by professional and governmental agencies for purposes such as the Register of Disabled Persons maintained by the Department of Employment as a result of the Disabled Persons (Employment) Acts, 1944 and 1958. These state that at least three percent of the employees of any firm employing more than 20 people must be registered disabled. (In practice, these acts do little to alter our status. Prosecutions under them are so rare as to be almost nonexistent; if a particular firm fills its quota deliberately, it is because it chooses to do so, not because it is being obliged to. So when we obtain work as a result of such a firm's compliance with the acts in question, we are still the recipients of charity rather than citizens exercising our rights.)

The Register of Disabled Persons does at least provide an objective measurement, being based on a medical examination designed to measure one's ability to work. In the kind of society - and, more particularly, the kind of economy - that we are living in, it is perhaps hardly surprising that a major criterion used in assessing disablement should be the ability to hold paid employment. What is not generally taken into account is that a person's ability or otherwise to hold a particular job is directly related to the provisions that are made for that person's physical needs. If a person in a wheelchair is unable to take an office job because there are steps up to the office building, are we to assume that the fault lies with the wheelchair-user for not being able to climb steps? I would say that the fault lies in the architecture. To present the problem in any other way is to condone the inadequacy of the existing arrangements and thus, in effect, to say that we have no right to expect anything better.

This is a type of attitude that feminists should find very recognisable, because similar arguments have frequently been used to limit women: girls can't play football, because there's only one changing room; we can't provide a crèche, because there isn't anywhere to put it; and so on. If any difference exists, it is perhaps that women can see more clearly when they are being treated in this way, because they receive such treatment in a slightly less wholesale fashion.

Obviously, no one with a disability which affects their mobility is unaware of access problems. But we take these things too calmly; we see them in terms of a failure to provide for our needs, with an implicit assumption that these needs are exceptional. (Because, deep down, hardly any of us really believe that we have a right to such provisions; we are well conditioned to think that we are asking for preposterous favours. Even if our reason rejects such ideas, our conditioning saps the rejection of its strength.) But what's so exceptional about being able to travel about freely, about being able to enter a public building without ringing a bell and waiting for someone to carry you up the stairs, about (in the case of deafness) being able to understand what's being said on television or at a public meeting? These things are not privileges, they are rights, fundamental human rights which we are being denied.

None of the examples I have cited would be particularly difficult to implement. They might prove costly in the short term, but so have most major reforms of the past: replacing slavery or child labour; building schools, as education became recognised as a fundamental right. The major difference is that, in our case, much of the necessary expenditure would be purely short-term: there's little point in building a school unless you're prepared to go on spending money on keeping it in operation, but no such problem arises when you build a ramp. It is financially an easier decision to take and has the advantage that no one is likely to close a ramp down for financial reasons

because it's being underused. Yet not only are we being denied these rights, we are being told that they do not exist, that the state of our bodies makes these things inapplicable to us.

It is not very long since Western nations treated some people as having no right to freedom because of the colour of their skins. When slavery was an institution, freedom (at least in a relative sense) was something that could be taken for granted - unless you were black; nowadays, mobility and communication can be taken for granted - unless you have certain kinds of disability. We have not really advanced very far. Whenever a person with a disability is classified incapable of performing a particular job, that classification constitutes a vote of confidence in the denial of whatever facilities would enable them to perform it.

In any case, this kind of definition is an unsatisfactory one for us to use in discussing our situation, because it is not based upon our needs, but upon our usefulness. Those of us who are defined as 'disabled' according to such criteria as these are being told that our economic value is more limited than that of 'normal' people. In the process, an artificial barrier is created, separating us from people whose disabilities do not affect their ability to work: people whose disabilities are 'not severe enough', or are under control with medication, and some people who would not be considered disabled at all by almost any conventional yardstick. Someone who has an obvious facial birthmark, for example, may not be physically incapacitated at all, but that does not save her from being subjected to the indignity of being stared at or, worse still, deliberately *not* stared at, like any other person with a visible disability. Are we to accept a definition of disablement which forces some of us to tell ourselves that we are not disabled? Are those of us who fall within this definition to say to such a person: 'We know you share our oppression, but we don't want you because you can work'? Or do we say: 'Welcome, friend, we know your pain, we share your anger'?

In rejecting the idea of accepting a definition based on the ability to work, 'I am not just attacking capitalism. A conventional Marxist analysis has equally little to say about people who are disqualified from being producers of surplus value. Certainly, I know of no group on the 'revolutionary Left' that takes disablement seriously. This does not come as any great surprise: such groups are notable for their failure to adjust to the shift of emphasis that has been taking place in radical politics to take account of the personal sphere of people's lives. Feminism has made a few dents in these remarkably entrenched attitudes, but women have on the whole come to the conclusion that it's less trouble to just get on with what needs doing. So have gays. So have radical educationalists. We may be out in the cold, but we're in good company.

Ultimately, *any* definition which separates people into 'disabled' and 'abled' is on one level extremely unsatisfactory, because it perpetuates what one might refer to as the 'myth of the normal healthy body'. This is the mechanism whereby disablement is seen in terms of a sharp dividing line: either you are physically normal, or you are disabled, the implication being that the latter is a much smaller category than the former.

But very few people have bodies that work with 100 percent efficiency. The myth is maintained by the acceptance of a range of minor physical abnormalities, such as short sight or hay fever, as compatible with normality. These exceptions do not reflect the degree to which an individual is incapacitated by the condition in question; they are made according to categories rather than individual cases. Thus, a person with severe hay fever may be greatly more incapacitated than a person who has mild or well controlled epilepsy, but is still more readily accepted as 'normal'.

In many cases, an acceptable condition implies a further fake clear-cut distinction, having been artificially manufactured by separating off one section of a group of disabilities of a particular kind. Thus, blindness and partial-sightedness are disabilities, short-sightedness is not. The true picture of disablement as a range of disorders of varying severity, each one covering a diversity of individual cases, is lost, and those 'below the line' are stigmatised.

It is noticeable that the status of 'disabled person' is very widely recognised as being distinct from the actual fact of disability. This can be seen in the process whereby many people rename or minimise their conditions to keep them 'above the line'. They refer to themselves as 'hard of hearing' rather than 'deaf', or 'very short sighted' rather than 'almost blind'. I would not condemn people who do this: coming out as disabled is not necessarily an easy process, particularly if one does not have any immediate contact with other people with disabilities, and it is very understandable that many people with disabilities choose to try to avoid the stigma attached to their particular disability rather than take a course of action which will inevitably confront them with the stigma. But I find it a matter for regret that people should feel they need to do this, because in struggling to pass as normals they cut themselves off from other people who have similar disabilities, and condemn themselves to isolation.

Related to this is the fact that such conditions as partial sightedness and partial hearing are named in a way that **connects** them with 'normality' rather than with the disabilities to which they are closely related.

I have sometimes come across a well intentioned argument for a change of attitude towards epilepsy - and would imagine that similar arguments are used in relation to other disabilities - which emphasises the mildness or controllability of most epileptics' symptoms. Superficially, this seems entirely reasonable. The fault in the argument is that it does not attack the stigma against epilepsy at its roots; it merely says that it is misapplied. A more radical approach is needed: we must demolish the false dividing line between 'normal' and 'disabled' and attack the whole concept of physical normality.

We have to recognise that disablement is not merely the physical state of a small minority of people. *It is the normal condition of humanity.* If there exists somewhere a person whose body is in immaculate working order - and I doubt very strongly whether such a being exists - then it is he or she who is the real statistical freak. And even so, she would not really be an exception to the rule, because such a state of fitness would be a purely temporary phenomenon. Any human being faces the prospect of ageing, with a consequent decline in physical ability. This alone will, in time, make any individual subject to discrimination based on physical condition.

Such discrimination, sometimes known, perhaps slightly clumsily, as 'ageism', includes: the making of assumptions about people's physical capabilities without reference to the actual facts; a further set of assumptions about mental capability; imposition of the idea that such people are not physically attractive; a failure to cater for people's physical needs. None of this differs from the general treatment of people who are defined as disabled. The fact that ageism has generally been treated as a separate issue is simply a measure of the extent of the acceptance of the false distinction between 'disabled' and 'able bodied'.

I regard this distinction as oppressive, but that is not to say that it is simply a question of people who are defined as disabled being oppressed by those who are defined, or define themselves, as able bodied. To be defined as able bodied is in itself a type of oppression primarily for the reason that, as I have explained, the supposedly 'able bodied' are in fact nothing of the sort. But the existence of this distinction hides the true nature of the situation and leads people to accept one of the two roles. Acceptance of the role of non-disabled person is something that the bulk of people have very little choice about; social pressures against 'making a fuss' about one's physical needs are extremely strong. Having accepted such a role, one has to live up to it.

And so people go on not making a fuss, assuming their own physical limitations are not severe enough for them to have a right to insist that their needs should be catered for, remaining alone with the distress caused by their

condition because they believe they are individual exceptions in a world full of 'normal' people.

I have a great deal of sympathy for people who class themselves as able bodied, because I used to be one of them. Even when I had started to consciously come out as epileptic, making a point of being as open as possible about the fact that I have fits, and started to see attitudes towards epilepsy as being linked with attitudes towards other types of physical disability, I retained a rather defensive feeling that I was making a slightly fraudulent claim. I still thought of epilepsy and 'physical' disability as separate, and did not really believe that having fits was as validly a disability as being in a wheelchair. But when I got to know people with other disabilities I found that I was accepted as an equal. It was only then that I really acquired confidence in my right to views which I had held for several years.

In rejecting the idea of a sharp dividing line between 'disabled' and 'able bodied', it is important that we remain extremely aware that this is not at all the same thing as the idea that 'we're all the same underneath'. Such attitudes do little to attack the way in which people with disabilities are treated, because they simply trivialise the issue, implying that if only able bodied people were a little more tolerant, there would be no problem. To try to pretend that disability does not exist does not solve any problems; such an attitude simply refuses to face them.

It is extremely important that we attack the division between 'disabled' and 'able bodied' and adopt a view of disablement that, in effect, says that everybody is disabled. But the fact remains that we live in a society where a minority of the population are particularly strongly discriminated against because of their disabilities. We therefore need a second, narrower, definition of disablement that refers specifically to this group of people (which is the group that this book is primarily about).

We need such a definition in order that those of us who are stigmatised because of our physical condition can recognise what we have in common and counteract our shared oppression by developing a group identity and a common awareness of our situation. The most useful basis for such a definition is the fact of stigmatisation itself. If we make no attempt to create a definition based on some type of measurement of physical incapacity, but simply define this group as consisting of all people who are stigmatised or discriminated against on the basis of their physical condition, we have an extremely practical rule of thumb definition.

A particular advantage of this definition is that it covers the groups of people I referred to earlier, who would be excluded from most definitions of disability

based on physical incapacity but who, because of conditions such as birthmarks or burn scars, are subjected to the same treatment as many people with more commonly recognised disabilities. It also covers people who are chronically sick, who are discriminated against in the form of inadequate provision for their needs and are particularly vulnerable to the effects of conditioning not to complain about physical pain.

This definition does not provide a precise scientific classification, which is good, because the group of people in question does not have sharp boundaries. But it is a useful working definition; when I refer to 'people with disabilities' in this book it is primarily this definition that I have in mind.