

Paul Hunt

Paul Hunt, aged 29, has six sisters, one of whom also has muscular dystrophy. He attended school until becoming chair-bound when he was thirteen, and then spent four and a half years in hospital. Since 1956 he has lived at the Cheshire Foundation Home in Hampshire, where he has plenty of work of various kinds and the stimulus of a very active community.

Mr Hunt has read a lot to supplement his curtailed education. He regularly contributes articles and reviews to the Cheshire Homes magazine. He is specially interested in the social and psychological aspects of disablement, and in the study of institutional life. Other interests include Christian theology and philosophy, the social sciences, literature and films. He gives his chief relaxations as talking, reading and sitting in the sun.

A Critical Condition

(Chapter 12 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).

ALL MY adult life has been spent in institutions amongst people who, like myself, have severe and often progressive physical disabilities. We are paralysed and deformed, most of us in wheel chairs, either as the result of accident or of diseases like rheumatoid arthritis, multiple sclerosis, muscular dystrophy, cerebral palsy and polio. So naturally this personal experience forms a background to the views on disability that follow.

I do not mean to exclude altogether the large number of people who today are able to lead a more or less normal life in the community; those with relatively light disabilities, or with such handicaps as defects in sight, speech or

hearing, epilepsy, obesity, heart disease, and so on. I hope that much of what I say will be relevant to this latter group since they have many problems in common with us.

But apart from the obvious value of writing from my own direct knowledge, it is also true that the situation of 'the young chronic sick' (as we are officially and rather unpleasantly termed) highlights, or rather goes to the depths of, the question of disablement. Our 'tragedy' may be only the tragedy of all sickness, pain and suffering carried to extremes. But disabilities like ours, which often prohibit any attempt at normal living in society, almost force one to consider the basic issues, not only of coping with a special handicap, but of life itself.

Being cheerful and keeping going is scarcely good enough when one has an illness that will end in an early death, when one is wasting away like some Belsen victim, maybe incontinent, dependent on others for daily needs, probably denied marriage and a family and forced to live out one's time in an institution. In these circumstances the most acute questions arise and the most radical 'answers' are called for.

I am not suggesting that all of us with such devastating handicaps probe deeply into the meaning of life, nor that we automatically gain great wisdom or sanctity. We have our defences like anyone else. But it does seem that our situation tends to make us ask questions that few people ask in the ordinary world. And it also means that to some extent we are set apart from, or rather have a special position within, the everyday society that most people take it for granted they belong to.

I want to look at this special situation largely in terms of our relations with others, our place in society. This is essentially related to the personal aspect of coping with

disablement, which I hope it will at the same time illumine, since the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with 'normal' people. If everyone were disabled as we are, there would be no special situation to consider.

This focus on the ways in which we are set apart from the ordinary does not mean that I see us as really separated from society. In fact the reverse assumption underlies everything I write. We are society, as much as anybody, and cannot be considered in isolation from it.

I am aware of the danger of concentrating on the ways in which disability makes us like each other and unlike the normal, and thus being trapped into the common fault of viewing people in terms of one characteristic to the exclusion of all others. Disabled people suffer enough from that kind of thing already. But whatever the differences between us, we do have certain sets of experiences in common. In dealing with this aspect of our lives I have tried not to forget two others - our uniqueness as persons and the human nature we share with the rest of mankind.

I think the distinguishing mark of disabled people's special position is that they tend to 'challenge' in their relations with ordinary society. This challenge takes five main forms: as unfortunate, useless, different, oppressed and sick. All these are only facets of one situation, but here it seems worth taking each in turn.

The first way in which we challenge others is by being unfortunate. Severely disabled people are generally considered to have been unlucky, to be deprived and poor, to lead cramped lives. We do not enjoy many of the 'goods' that people in our society are accustomed to. The

opportunity for marriage and having children, authority at home and at work, the chance to earn money, independence and freedom of movement, a house and a car¹ - these things, and plenty more may be denied us.

Underprivileged as we are in this sense, one point seems to be clear. If the worth of human beings depends on a high social status, on the possession of wealth, on a position as parent, husband or wife - if such things are all-important-then those of us who have lost or never had them are indeed unfortunate. Our lives must be tragically upset and marred for ever, we must be only half alive, only half human. And it is a fact that most of us, whatever our explicit views, tend to act as though such 'goods' are essential to a fully human existence. Their possession is seen as the key to entry into a promised land of civilized living.

But set over against this common sense attitude is another fact, a strange one. In my experience even the most severely disabled people retain an ineradicable conviction that they are still fully human in all that is ultimately necessary. Obviously each person can deny this, and act accordingly. Yet even when he is most depressed, even when he says he would be better off dead; the underlying sense of his own worth remains.

This basic feeling for the value of the person as such becomes fully operational, as it were, when those with severe disabilities live full and happy lives in defiance of the usual expectations. An increasing number of people do seem to overcome their misfortunes like this, and it is they who present the most effective challenge to society.

When confronted with someone who is evidently coping with tragic circumstances, able-bodied people tend to

¹ I do not mean to imply that all these 'goods' are of the same order

deny the reality of the adjustment. The disabled person is simply making the best of a bad job, putting a good face on it. There may be some truth in this. But when it becomes obvious that there is also a genuine happiness, another defensive attitude is taken up. The 'unfortunate' person is assumed to have wonderful and exceptional courage (although underneath this overt canonization there is usually a degree of irritation and hostility which comes to light at moments of stress). This devalues other disabled people by implication, and leaves the fit person still with his original view that disablement is really utterly tragic.

Such reactions appear to be caused by the need to safeguard a particular scale of values, where someone's sense of security depends on this being maintained. He almost wants the disabled person to suffer, as a confirmation that the values denied him are still worthy and important and good. If he shows no obvious sign of suffering, then he must challenge people whose own worth seems to them to be bound up with their more fortunate position in life.

So if those of us who are disabled live as fully as we can, while being completely conscious of the tragedy of our situation-this is the possibility when one has an alert mind-then somehow we can communicate to others an awareness that the value of the human person transcends his social status, attributes and possessions or his lack of them. This applies however much we recognize these 'accidents' as important, and however much we regard the 'goods' I have mentioned as the normal elements in a full life. What we oppose is only the assumption that makes them absolutely indispensable for a completely human existence.

Perhaps we can help prepare people for the almost certain day when they themselves lose, at least in old age, some of the advantages that are so highly valued. But

anyway, those who implicitly believe that a man's worth depends on his good fortune must be building their lives on rather inadequate foundations, and they will perhaps find contact with us a thought-provoking experience.

A second aspect of our special position in society is that we are often useless, unable to contribute to the economic good of the community.

As such, again we cannot help posing questions about values, about what a person is, what he is for, about whether his work is the ultimate criterion of his worth, whether work in the everyday sense of the word is the most important or the only contribution anyone can make to society.

There is no doubt that we do put great stress on the individual's economic contribution. Most people are wrapped up in a workaday, utilitarian world, and regard anything not visibly productive as expendable. Contemplation, philosophy, wisdom, the liberal arts, get short shrift from the average man. Those who cannot work, such as the sick, aged or unemployed, are subject to a tremendous pressure to feel useless, or at least of less value than the breadwinner.

I am not indicting some abstract Society for getting its priorities wrong; each of us shares responsibility for the prevailing attitudes. Also I am far from saying that work, in the sense of contributing to the wealth of the community, is unimportant. Of course willingness to pull one's weight is an essential part of a healthy and balanced outlook on life and other people.

But I am concerned that we should not elevate the idea of work in our minds to the point where it dominates values that ought to transcend it. It is important not to do this, if

only because it causes the most acute suffering in those of us who cannot help being parasites on the economic body.

Obviously we who are disabled are deeply affected by the assumptions of our uselessness that surround us. But it is vital that we should not accept this devaluation of ourselves, yearning only to be able to earn our livings and thus prove our worth. We do not have to prove anything.

If we have a basic willingness to contribute to the community, yet cannot do an ordinary job, we may certainly contribute in less obvious ways; even, and perhaps especially, if these seem insignificant beside the 'real world of work'. Our freedom from the competitive trappings that accompany work in our society may give us the opportunity to demonstrate its essential elements. Also we can act as a symbol for the pre-eminent claims of non-utilitarian values, a visible challenge to anyone who treats his job as a final end in itself. And we do of course afford people the chance to be generous in support of the needy, thus enabling them to give practical expression to their desire to go beyond the acquisitive instinct.

At the ultimate point we may only be able to suffer, to be passive through complete physical inability. Just here we have a special insight to offer, because our position gives us an extra experience of life in the passive aspect that is one half of the human reality. Those who lead active lives are perhaps especially inclined to ignore man's need to accept passivity in relation to so many forces beyond his control.. They may need reminding, sometimes of our finiteness, our feminine side in the hands of fate or providence. We are well placed to do this job at least.

The next challenging characteristic of the disabled is that we are different, abnormal, marked out as members of a minority group.

Normality is so often put forward as the goal for people with special handicaps, that we have come to accept its desirability as a dogma. But even if one takes a common sense meaning for the word-being like most people in our society-it is doubtful if this is what we should really fix our sights on. For one thing it is impossible of achievement, at certain levels anyway. Obviously we cannot be physically normal, are doomed to be deviants in this sense at least. Also we must be affected psychologically by our disabilities, and to some extent be moulded into a distinct class by our experiences.

But more important, what kind of goal? this elusive normality. If it does mean simply trying to be like the majority, then it is hardly a good enough ideal at which to aim. Whether they are physically handicapped or not, people need something more than this to work towards if they are to contribute their best to society and grow to maturity.

Of course there is a certain value in our trying to keep up with ordinary society, and relate to it; but it is essential to define the sense in which this is a good thing. Once more I am not rejecting in a sour-grapes spirit the many excellent normal goals that may be denied us-marrying, earning one's living, and so on. What I am rejecting is society's tendency to set up rigid standards of what is right and proper, to force the individual into a mould. Our constant experience of this pressure towards unthinking conformity in some way relates us to other obvious deviants and outcasts like the Jew in a gentile world, a Negro in a white world, homosexuals, the mentally handicapped; and also to more voluntary rebels in every sphere-artists,

philosophers, prophets, who are essentially subversive elements in society. This is another area where disabled people can play an important role.

Those we meet cannot fail to notice our disablement even if they turn away quickly and avoid thinking about us afterwards. An impaired and deformed body is a 'difference' that hits everyone hard at first. Inevitably it produces an instinctive revulsion, has a disturbing effect.

Our own first reaction to this is to want to hide ourselves in the crowd, to attempt to buy acceptance on any terms, to agree uncritically with whatever is the done thing. Feeling excessively self-conscious we would like to bury ourselves in society away from the stares of the curious, and even the special consideration of the kindly, both of which serve to emphasize our difference from the majority.

But this very natural impulse has to be resisted. We must try to help people accept the fact of our unavoidable difference from them - which implies that we are attempting to integrate it within ourselves too. However, this does not mean just creating a comfortable atmosphere of acceptance around ourselves, building up a circle of able-bodied friends who treat us right, and trying to leave it at that. It is imperative that the effort should be followed through to the point where we, and those we come into contact with, understand that it is not just a case of our minds compensating for our disabilities, or something like that.

We can witness to the truth that a person's dignity does not rest even in his consciousness, and certainly that it does not rest in his beauty, age, intelligence or colour. Those of us with unimpaired minds but severely disabled bodies, have a unique opportunity to show other people not only that our big difference from them does not lessen

our worth but also that no difference between men, however real, unpleasant and disturbing, does away with their right to be treated as fully human.

We face more obviously than most the universal problem of coming to terms with the fact of man's individuality and loneliness. If we begin to accept our own special peculiarity, we shall be in a position to help others accept even their own difference from everyone else. These two acceptances are bound up together.

People's shocked reactions to the obvious deviant often reflect their own deepest fears and difficulties, their failure to accept themselves as they really are, and the other person simply as 'other'.

The disabled person's 'strangeness' can manifest and symbolize all differences between human beings. In his relations with more nearly normal people he may become a medium for reconciling them to the fact of these differences, and demonstrate their relative unimportance compared to what we have in common.

The fourth challenging aspect of our situation follows inevitably from our being different and having minority status. Disabled people often meet prejudice, which expresses itself in discrimination and even oppression.

Sometimes it seems to us that we just can't win. Whatever we do, whether good or bad, people put it down to our being disabled. Meeting this kind of attitude constantly can be depressing and infinitely wearing. You may produce the most logical and persuasive arguments only to have them dismissed, without even the compliment of counter-argument, as products of your disability. The frustrating thing is that there is no appeal against this. If you point out what is happening you are assured it isn't, that you are

imagining a prejudice which does not exist. And immediately you know you are branded again as being unrealistic and impossibly subjective. So many people take it for granted that what you say can be explained by a crude theory of compensation, and therefore is of no account or self-evidently false. And they tell themselves that you can't really help having these ideas, poor thing.

One rather doubtful pleasure is to discover that this 'poor thing' attitude does not survive a determined rejection of the able-bodied person's assumption of inherent superiority. He admits equality as a theory, but when you act as though you are equal then the crucial test comes. Most people are good-willed liberals towards us up to this point, but not all of them survive close contact with disability without showing some less attractive traits. "Of course it is not only the 'fit' who are like this. I know I have instinctive prejudices against lots of people; against the able-bodied to start with. It is a basic human characteristic to fear and put up barriers against those who are different from ourselves. Without for a moment justifying any of its manifestations, it seems to me just as 'natural' to be prejudiced against someone with a defective body (or mind) as it is to have difficulty in accepting the members of another racial group.

Maybe it is invidious to compare our situation with that of racial minorities in any way. The injustice and brutality suffered by so many because of racial tension makes our troubles as disabled people look very small. But I think there is a connection somewhere, since all prejudice springs from the same roots. And there stirs in me a little of the same anger as the Negro writer James Baldwin reveals in *The Fire Next Time*² when I remember the countless times I have seen disabled people hurt, treated as less than people, told what to do and how to behave by

² Penguin Books 1964

those whose only claim to do this came from prejudice and their power over them.

In the hospitals and Homes I have lived in one rarely sees any physical cruelty. But I have experienced enough of other kinds of subtly corrupting behaviour. There are administrators and matrons who have had people removed on slight pretexts, who try to break up ordinary friendships if they don't approve of them. There are the staff who bully those who cannot complain, who dictate what clothes people should wear, who switch the television off in the middle of a programme, and will take away 'privileges' (like getting up for the day) when they choose. Then there are the visitors who automatically assume an authority over us and interfere without regard for our wishes.

Admittedly some of these examples are trivial, and I have not mentioned all the excellent people who make any sort of life possible for us. But still I think it is true that we meet fundamentally the same attitude which discriminates against anyone different and shades off into oppression under the right-or rather wrong-conditions.

In the wider community the similarity is even clearer. Employers turn away qualified and competent workers simply because they are disabled. Restaurants and pubs give transparent excuses for refusing our custom. Landladies reject disabled lodgers. Parents and relations fight the marriage of a cripple into their family-perhaps with more reason than with a black African, but with many of the same arguments. And it's not hard to see the analogy between a racial ghetto and the institutions where disabled people are put away and given enough care to salve society's conscience.

Of course there are vast differences between our situation and that of many other 'downtrodden' people. One of

these is that we are not a potential threat to lives and property. For this reason alone we can be hopeful that at least our freedom from open discrimination³ can be achieved even though we shall never have sufficient power in the community to ensure this. It also gives us a good chance of avoiding the ever-present danger for those who are oppressed-that they will pay homage to the same god of power that is harming their oppressors. It is true that we still have to solve the problem of means and ends; of whether, or rather in what way, we should oppose evil. But perhaps precisely because violence and power-seeking are not really practical possibilities for us, we are well placed to consider other ways of achieving freedom from injustice. However, we should be careful that our weakness here does not become an excuse for a sterile resignation.

One reason why we must resist prejudice, injustice, oppression, is that they not only tend to diminish us, but far more to diminish our oppressors. If you try to care about people you cannot be indifferent to what is happening to those who treat you badly, and you have to oppose them. If this opposition is to be by means of patience and long-suffering, then they must be directed at the abolition of evil or they are just forms of masochism.

In this section I have not only been drawing an analogy between our position in society and that of racial minorities, but also pointing the connection between all the manifestations of prejudice and discrimination. This connection means that although we cannot directly assist the American Negro, for instance, in his resistance to oppression, in one way we can help everyone who suffers injustice.

³ The elimination of prejudice is not really possible: a helpful social climate can only do so much, and each individual and generation has to renew a fight that cannot be won.

We do this above all by treating properly those we meet. There are always people we feel superior to or resent—the mentally ill, the aged, children, those who patronize us or hurt us. If we do not try to treat all these as fully human beings, then it is certain we would not be able to help the Negro or anyone else in a similar predicament. Here, as in so many instances, it is true that: 'What we do is a symbol of what we would do. Not only can we do no more than to let an act substitute for a more splendid act, *but no one can do more*. This is the reconciliation.'⁴

The last aspect of our challenge to society as disabled people is that we are sick, suffering, diseased, in pain.

For the able-bodied, normal world we are representatives of many of the things they most fear—tragedy, loss, dark and the unknown. Involuntarily we walk—or more often sit—in the valley of the shadow of death. Contact with us throws up in people's faces the fact of sickness and death in the world. No one likes to think of such things, which in themselves are an affront to all our aspirations and hopes. A deformed and paralysed body attacks everyone's sense of well-being and invincibility. People do not want to acknowledge what disability affirms—that life is tragic and we shall all soon be dead.⁵ So they are inclined to avoid those who are sick or old, shying from the disturbing reminders of unwelcome reality.

Here I would suggest that our role in society can be likened to that of the satirist in some respects. Maybe we have to remind people of a side of life they would sooner forget. We do this primarily by what we are. But we can intensify it and make it more productive if we are fully conscious of the tragedy of our situation, yet show by our lives that we believe this is not the final tragedy.

⁴ Doris Lorenzen in *Experiments in Survival*, Kriegel, New York

⁵ I do not intend to discuss explicitly religious or philosophical questions in this essay, but obviously the possibility of a life after death must be extremely relevant at this point.

Closely involved with death and dark in the unconscious and subconscious, though really distinct, is the idea of evil. An almost automatic linkage is made not only between a sick body and a sick mind, but also undoubtedly between an evil body and an evil mind, a warped personality.

There is a definite relation between the concepts of health and holiness. So many of the words used about health are moral ones - we talk of a good or bad leg, of being fit and unfit, of walking properly, of perfect physique. And disabled people find that the common assumption of good health as a natural thing often comes over to us as an 'ought', carries with it undertones of a moral failure on our part. 'If only you had enough will-power...' is the modern-dress version of the idea that we are possessed by an evil spirit.

Then there are traces of a desire to externalize evil, to find a scapegoat, in attitudes to the sick. Sometimes people are evidently trying to reassure themselves that they are 'saved', justified, in a state of grace. I do not mean just the feeling of gaining merit from charitable works, but rather a satisfaction got from their 'good' selves juxtaposed with the 'unclean', the untouchables, who provide them with an assurance that they are all right, on the right side.

No doubt this process works the other way too. Our experience of subjection as sick people may give us a sense of being holy and predestined in contrast to our condescending, prejudiced fellow men. But such attitudes; whether in ourselves or others, have to be constantly resisted and rooted out. They are simply products of our own fears and weaknesses, and any temporary security they give is false and dangerous.

I have dealt briefly with five interrelated aspects of disabled people's position as a challenge to some of the common values of society: as unfortunate, useless, different, oppressed and sick.

A paradoxical law runs through the whole of the situation I have been describing. It is that only along the line of maximum resistance to diminishment can we arrive at the required point for a real acceptance of what is unalterable. We have first to acknowledge the value of the good things of life of prosperity, usefulness, normality, integration with society, good health- and be fully extended in the search for fulfilment in ordinary human terms, before we can begin to achieve a fruitful resignation.

Nowadays many disabled people will have nothing to do with resignation as it used to be understood. Thriving in a climate of increasing public tolerance and kindness, and on a diet of pensions and welfare, we are becoming presumptuous. Now we reject any view of ourselves as being lucky to be allowed to live. We reject too all the myths and superstitions that have surrounded us in the past.

We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself. We do not want ourselves, or anyone else, treated as second-class citizens and put away out of sight and mind.

Many of us are just beginning to refuse to be put away, to insist that we are part of life too. We are saying that being deformed and paralysed, blind or deaf - or old or mentally sick for that matter - is not a crime or in any meaningful sense of the words a divine punishment. Illness and impairment are facts of existence, diminishment and death are there to be thought about and must be taken account

of in any realistic view of the world. We are perhaps also saying that society is itself sick if it can't face our sickness, if it does not overcome its natural fear and dislike of unpleasantness as manifested by disability.

We are asking of people something that lies a lot deeper than almsgiving. We want an extension of the impulse that inspires this, so that it becomes a gift of self rather than the dispensing of bounty (material and other kinds) from above. To love and respect, treat as equals, people as obviously 'inferior' as we are, requires real humility and generosity. I believe that our demand to be treated like this is based on a truth about human beings which everyone needs to recognize - which is why we have a particularly important function here. But there is also no doubt that acquiring and maintaining such an attitude runs contrary to some of people's most deep seated impulses and prejudices.

The quality of the relationship the community has with its least fortunate members is a measure of its own health. The articulate person with a severe disability may to some extent represent and speak on behalf of all those who perhaps cannot interpret their predicament, or protest for themselves-the weak, sick, poor and aged throughout the world. They too are rejects from ordinary life, and are subject to the same experience of devaluation by society.

This linkage with other 'unfortunates', with the shadow side of life, is not always easy to accept. For the disabled person with a fair intelligence or other gifts, perhaps the greatest temptation is to try to use them just to escape from his disabledness, to buy himself a place in the 'sun, a share in the illusory normal world where all is light and pleasure and happiness. Naturally we want to get away from and forget the sickness, depression, pain, loneliness and poverty of which we see probably more than our

share. But if we deny our special relation to the dark in this way, we shall have ceased to recognize our most important asset as disabled people in society-the uncomfortable, subversive position from which we act as a living reproach to any scale of values that puts attributes or possessions before the person.