Foreword

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

This is an uncomfortable book.   Firstly, it is uncomfortable because it reveals how inadequate are the existing services for the disabled in Britain. Pensions are not paid to many persons, particularly to housewives, who need them. The amounts that are paid are generally too small and they vary unfairly according to whether the disability was incurred in war, industry or civil life. Payments for dependent children are poor when compared, for example, with those by local authorities for foster children. Information about aids to disability, specially designed housing and household gadgets is hard to obtain. Voluntary and statutory organisations concentrate too much on publicity 'shows'-like parties and Christmas visits, parcels and pantomimes- instead of continuing care - such as home help, physiotherapy, hydrotherapy and supporting help for relatives at holidays and other times. The Disabled Persons Employment Act has proved of small value to those other than the less seriously disabled. Many persons have little help either from employers or Disablement Resettlement Officers.

Secondly, the book is uncomfortable because it shows that these inadequacies are not just unwitting gaps in the outer fabric of the Welfare State which would be filled if called to public attention. They reflect a much deeper problem of a distortion of the structure and of the value-system of society itself. Achievement, productivity, vigour, health and youth are admired to an extreme. Incapacity, unproductiveness, slowness and old age are implicitly if not explicitly deplored. Such a system of values moulds and reinforces an elaborate social hierarchy. The disabled are as much the inevitable victims of this system as the

young professional and managerial groups are its inevitable beneficiaries. The question that is therefore raised is not a straightforward one. It is complicated and immense. Is it possible to secure real gains for those who are disabled without calling for a reconstruction of society and schooling new attitudes in the entire population?

Several of the writers of the following essays dwell on this problem. Although they describe the miserable lack of facilities and services this is not what worries them most. They keep coming pack to the qua1ity of the human re1ationships which lie behind. They are concerned not only about relations with husbands, wives, children and friends but with workmates, neighbours and the rest of the community. They realize how widespread are feelings of protectiveness, superiority, aloofness and even revulsion towards them. Ordinary people often expect them to become passive and compliant independents, an isolated category of the pitied who are thrust out of sight at home or in institutions no wonder they write of the bitterness and frustration involved in playing the role of invalid.

Many struggle instinctively against this stigmatization. They refuse to reconcile themselves to a separate life and status. 'Our longing to have a real place in society … indicates that we are not meant to live as isolated beings.' 'The partially disabled person ... needs to become part of "normal' society and not isolated among his own kind.' And again, 'Society has to realize that first and foremost we are people equally with the non-disabled. Our social needs and aspirations are identical with theirs.'   These extracts from three of the essays show how powerful is the desire for integration with ordinary social groups. The disabled tend to dislike self-conscious togetherness as much as ostrich-like security. If only special types of housing were available in ordinary neighbourhoods and steps could be taken to fit them into ordinary forms of

employment, clubs and societies instead of segregated workshops and institutions, their view is that the social stigma from which they suffer would gradually be removed.

This does not mean they want to be treated as if their disabilities did not exist. On the contrary, many feel that their difference from, other people has to be acknowledged realistically by both themselves and by others. They feel they will gain nothing by disguising their limitations. If they are to adjust successfully to disability they have to accept less than full membership of society. And, equally, if the non-disabled are to adjust to them then some diminution of privilege has to be accepted. Social justice involves some people's loss as well as others' gain.

One remarkable feature of these essays is the insight given into the nature of the individual's relationships with society. The authors continually reach beyond the immediate problems of persons who happen to suffer from muscular dystrophy, rheumatoid arthritis or the effects of poliomyelitis. They show that adjusting to disability is simply a special version of the universal problem of adjusting to personal short-comings and loneliness Those who are disabled experience in an extreme form the self-consciousness, inadequacy and pain which touches at certain times and in varying degree all mankind. As Paul Hunt writes, 'Our "tragedy" may be only the tragedy of all sickness, pain and suffering.' To some readers this may seem to be a forlorn, if brave, message of hope, but it seems to me to be fundamentally correct. Disability, like intelligence, is more a matter of degree than of kind. It is more a relative than an absolute condition. If this is correct then our conception of human diversity has merely to be extended beyond the customary limits. And the conclusion that has to be drawn is that fewer of the disabled should be sheltered from the mainstreams of life and more of

them integrated with society. This would benefit not only the disabled. Many in the population would be encouraged to overcome I their fear and shock of disability and would be helped thereby to come to terms with their own shortcomings and see more clearly their own relationships with the community.

Another feature of these essays is the authors' assertion of the need for a fresh interpretation of social equality. They disentangle themselves from conventional expressions of gratitude for services rendered and propose introducing new patterns of rights into a situation which has traditionally been dominated by condescension and patronage on the one hand and inferiority or deference on the other.   By insisting on these rights they are saving many from a benevolent but indifferent superiority and laying the basis for a general pattern of more equal and less discriminatory social relationships. Some new but important steps have been taken to establish a common humanity. "

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Introduction

MUCH OF the writing by people with physical handicaps is either sentimental autobiography, or else preoccupied with the medical and practical details of a particular affliction. This book is an attempt to explore the experience of disability rather more realistically and at greater depth.

The eleven essays included with my own were chosen from the sixty I received after a letter published in several national papers and magazines. These contributions were selected, not because I agreed with everything the authors say, but because I thought they treated the subject honestly, coherently and from a useful variety of angles. Taken as a whole they make a striking blend of vivid accounts of personal experience and valuable insights into many of the dilemmas inherent in our situation.

We can hardly claim to be representative of the disabled in general, since disability hits at random and affects people with every kind of ability and attitude and in all sorts of circumstances. None of us have such common handicaps as blindness or deafness. But given the purpose of the book these limitations are not really important. I think we succeed in conveying what it is like to be permanently disabled in our society, with special reference to our inescapable involvement in a strange world of deep-rooted feelings and assumptions about sickness and deformity. We provide, too, an example of the way an increasing number of handicapped people are thinking about their predicament. The distinctive feature of this development is an awareness that there is really no such thing as a disabled person, only people who have disabilities. This may seem a truism. Yet the shift of emphasis from the disability to the person has far-reaching implications.

Despite our differences on various points, the twelve of us share a desire for recognition as individuals whose disablement is one important influence on our personalities, but only one - like our nationality, age or education. We are tired of being statistics, cases, wonderfully courageous examples to the world, pitiable objects to stimulate fund-raising.

It follows that we hope our contributions to this book will be treated on their merits, and neither praised nor dismissed simply on the basis of sympathy or of prejudice. We ask the reader to measure what we say against his own experience and understanding, and decide on those grounds to what extent it is true or false. If we manage to stimulate criticism of this kind then the object of Stigma will be achieved.

Paul Hunt