

1 Introduction

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

Over the last few years, a new, more uncompromising mood has been springing up among people with disabilities. Increasingly, we are jettisoning passive acceptance of our situations, taking pride in our selves and our bodies, and coming to see ourselves as disabled, if we are disabled at all, not by the idiosyncrasies of our bodies but by a society which is not prepared to cater to our needs. Many of us have drawn strength from encountering the arguments of (in particular) black consciousness and feminism and realising that much of what was being discussed related to our own situations as people with disabilities.

This book is an attempt to reflect that mood and present what we feel about our disabilities and about disablement in general, together with some of the conclusions our experience has led us to about our position in society.

I could not have written this book in isolation; though I started a good many years ago to form opinions of my own situation as a person who is subject to epileptic fits, my present thinking about disablement has been informed and influenced by the exchange of ideas and information with other people with disabilities, and by the experiences we have shared in working together for change. In particular, I would once have been much less confident of my right to speak for people with disabilities other than my own; at one time, while having fairly well worked-out ideas about epilepsy (which have not since altered radically) and thinking of myself as a person with a disability, I was not at all sure that people with other disabilities would accept epilepsy as a 'real' disability.

That feeling was partly a recognition that I did not then know many other people with disabilities, partly a belief - which I still hold - that one should not generalise about any given disability without knowing how people who actually have that disability have defined their situation. But it was largely a false doubt, and I now realise that a great many people with disabilities are held back by feelings that they somehow don't count, that they don't have a disability or that their disability is not severe enough for them to have a right to complain. Such feelings are the result of our oppression as people with disabilities, and are among the many things we have to help each other to overcome. I doubt very much whether this book would have been written were it not for the other people with disabilities who gave me the ready acceptance and support which enabled me to overcome some of those attitudes myself.

In writing *Disabled We Stand*, I have taken a variety of opinions and analyses which I know to be current among certain people with disabilities and which I regard as important, and placed these, along with observations of my own, within the structure of an extended argument. I have drawn heavily upon a series of tape recorded interviews with other people with disabilities, which I carried out for the book. All the names used are real names, with one exception. In the event, I chose to carry out a relatively small number of interviews, making them lengthy enough to allow people to talk in detail about what concerned them, rather than a larger number of more superficial interviews in the hope of achieving some sort of representative cross-section of disability. One reason for this decision was my awareness that it would be very misleading to imply that any disability can be summed up in one person's experience: we are already quite dehumanised enough in this fashion as it is. We are all individuals, with an individual set of physical and emotional needs and a distinct personal experience of the disability we share with other people; in the case of epilepsy, I have indicated this fact by interviewing someone whose experience of epilepsy is very different from my own.

The people I interviewed were all people I knew to be broadly in agreement with the set of ideas I was planning to advance in this book. It was, I felt, important that the book should contain some explanation of the nature of each person's disability. Rather than go through a detailed description each time I quoted from one of the interviews, I asked all the people who spoke to me to write a short personal statement; these can be found in Appendix 1. All the people quoted have had the opportunity to read as much of the manuscript as they wished (which, in several cases, has meant all of it) to check for inaccuracy and any statements they might wish to withdraw or modify, and to examine the context in which their statements had been used. I made alterations where requested; on the rare occasions where changes were asked for which I thought would be mistaken, we discussed the matter, but the final right of veto always lay with the person quoted. I had stated that this would be the case before starting each interview.

I must emphasise that all these people have contributed far more to this book than the passages I have quoted; in one instance I dropped an entire planned chapter as a result of a single perceptive comment. While I take the final responsibility for the contents of this book, it would, therefore, be a mistake to regard me as some sort of isolated expert on having a disability. I shall regard any attempt to do so as thoroughly divisive, and harmful both to me personally and to people, with disabilities in general. My qualification for writing this book was not that I had any greater right to speak than any other person with a disability, but that I had the same right. I see *Disabled We Stand* as one contribution to a continuing discussion, which I hope will be carried a good deal further than I have carried it here.

There is one area of disability which I have deliberately avoided discussing: this book does not cover the issues relating to mental handicap. Though I definitely regard this as a disability within the meaning of the term as I have used it, I have not included any discussion of it because it seemed to me that the problems involved in fitting it into the sort of framework of ideas I have outlined would be more complex than I had room to discuss or experience to make sound judgements on. In particular, my basic assumption that we should be in charge of the decisions that affect our lives would need some modification in many cases (though probably much less than might be assumed). But one thing is certain: people with mental handicaps are capable of a great deal more self-dependence than they are generally conceded at present. An important part of our further development will be the working out of strategies for making ourselves good allies to people with mental handicaps, recognising that their oppression is our oppression and sharing our growing strength to help them find that self-dependence.

I have no doubt whatsoever that what is said in this book will, in some quarters, arouse accusations of bitterness, chips on our shoulders and failure to 'adjust to our situations'. It's nothing of the sort, of course, but simply the insight and anger of people whose degree of acceptance of their disabilities is such that they have the confidence to stipulate what they expect from other people and the society in which they live. But there are many able bodied, or supposedly able bodied, people who find it very threatening to be faced with signs of our strength. That's tough, because they're going to be seeing more and more of it from now on.

Ultimately, this is a book with very wide implications, because, implicitly and explicitly, it asks what sort of society we want to live in. When I can lie semi-conscious in the street after a fit while other people walk past, when thousands of millions of pounds can be spent on armaments while large numbers of people are being denied the aids which would give them such basic rights as mobility or adequate communication, it's time we started working out where we went wrong. The changes that will make a better society for people with disabilities to live in will make a better society for everybody to live in.