

# Disabling Barriers - Enabling Environments

Third Edition

edited by  
**John Swain, Sally French,  
Colin Barnes & Carol Thomas**

 **SAGE**

Los Angeles | London | New Delhi  
Singapore | Washington DC



Los Angeles | London | New Delhi  
Singapore | Washington DC

SAGE Publications Ltd  
1 Oliver's Yard  
55 City Road  
London EC1Y 1SP

SAGE Publications Inc.  
2455 Teller Road  
Thousand Oaks, California 91320

SAGE Publications India Pvt Ltd  
B 1/1 Mohan Cooperative Industrial Area  
Mathura Road  
New Delhi 110 044

SAGE Publications Asia-Pacific Pte Ltd  
3 Church Street  
#10-04 Samsung Hub  
Singapore 049483

---

Editor: Kate Wharton  
Assistant editor: Emma Milman  
Production editor: Katie Forsythe  
Copyeditor: Sharon Cawood  
Proofreader: Neil Sentance  
Indexer: Anne Fencott  
Marketing manager: Tamara Navaratnam  
Cover designer: Wendy Scott  
Typeset by: C&M Digital (P) Ltd, Chennai, India  
Printed in India at Replika Press Pvt Ltd

Editorial arrangement and introduction © John Swain, Sally French, Colin Barnes and Carol Thomas 2014  
Chapter 1 'A Critical Condition' © Paul Hunt 1966  
Chapter 1 'The Helped/Helper Relationship' © Vic Finkelstein 1981  
Chapter 2 © Carol Thomas 2014  
Chapters 3 and 6 © Colin Barnes 2014  
Chapter 4 © Colin Cameron 2014  
Chapter 5 © Colin Goble 2014  
Chapter 7 © John Swain and Sally French 2014  
Chapter 8 © Bill Hughes 2014  
Chapters 9 and 18 © Dan Goodley 2014  
Chapters 10, 23 and 42 © Alison Sheldon 2014  
Chapter 11 © Steve Robertson and Brett Smith 2014  
Chapter 12 © Liz Crow 2014  
Chapters 13 and 33 © Donna Reeve 2014  
Chapter 14 © Mark Priestley 2014  
Chapter 15 © Robert Williams-Findlay 2014  
Chapter 16 © Alison Wilde 2014  
Chapter 17 © Yasmin Hussain 2014  
Chapter 19 © Selina Bonnie 2014

Chapter 20 © Dawn Benson and Sarah Keyes 2014  
Chapter 21 © John M. Davis 2014  
Chapter 22 © Laura Hemingway 2014  
Chapter 24 © Alan Hewitt and Carole Pound 2014  
Chapter 25 © Michele Moore 2014  
Chapter 26 © Sally French 2014  
Chapter 27 © Hannah Morgan 2014  
Chapter 28 © Donna Marie Brown, Pauline Gertig, Maureen Gillman, Joyce Anderson, Cathy Clarke and Simon Powell 2014  
Chapter 29 © Brett Smith and Anthony Papatomas 2014  
Chapter 30 © Ann Macfarlane 2014  
Chapter 31 © Alan Roulstone 2014  
Chapter 32 © Sarah Woodin 2014  
Chapter 34 © Peter Beresford 2014  
Chapter 35 © Maria Berghs 2014  
Chapter 36 © Sally French and John Swain 2014  
Chapter 37 © Rob Imrie 2014  
Chapter 38 © Alice Maynard 2014  
Chapter 39 © Bill Ahmer 2014  
Chapter 40 © Pam Thomas 2014  
Chapter 41 © Marcia Rioux and Bonita Heath 2014

First edition published 1992, reprinted in 2002 and 2003.  
Second edition published 2004, reprinted in 2007, 2008, 2009, 2010 and 2011.  
This edition first published 2014

Apart from any fair dealing for the purposes of research or private study, or criticism or review, as permitted under the Copyright, Designs and Patents Act, 1988, this publication may be reproduced, stored or transmitted in any form, or by any means, only with the prior permission in writing of the publishers, or in the case of reprographic reproduction, in accordance with the terms of licences issued by the Copyright Licensing Agency. Enquiries concerning reproduction outside those terms should be sent to the publishers.

**Library of Congress Control Number: 2013934995**

**British Library Cataloguing in Publication data**

A catalogue record for this book is available from the British Library

ISBN 978-1-4462-5898-9  
ISBN 978-1-4462-5899-6 (pbk)

# 1

## An Historical Overview

The following abridged chapters by Paul Hunt and Vic Finkelstein aim to give an historical perspective to the field of disability studies. Both of these authors were leading figures within this field and have contributed to it hugely.

### A Critical Condition

Paul Hunt

(Hunt, P. (1966) 'A critical condition', in P. Hunt (ed.), *Stigma: The Experience of Disability*. London: Geoffrey Chapman. Abridged by Sally French.)

All my adult life has been spent in institutions amongst people who, like myself, have severe physical disabilities. So naturally this personal experience forms a background to the views on disability that follow. 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 that disabilities like ours, which often prohibit any attempt at normal living in society, almost force one to consider the basic issues, not only coping with a handicap, but with life itself.

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 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.

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

The first way we challenge others is by being unfortunate. 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 car – these things, and plenty more, may be denied us.

But set 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. This becomes fully operational when those with severe disabilities live full and happy lives in defiance of the usual expectations. 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 deny the reality of the adjustment. The disabled person is simply making the best of a bad job, putting a good face on it. 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. 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. So if those of us who are disabled live as fully as we can, we can communicate to others an awareness that the value of the human person transcends his social status, attributes or possessions or his lack of them.

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 work is the most important contribution anyone can make to society. 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. We do not have to prove anything. 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. Those who lead active lives are perhaps especially inclined to ignore man's need to accept passivity in relation to so many facets 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 often put forward as the goal for people with handicaps. But it is doubtful if this is what we should really fix our sights on. If it means simply trying to be like the majority, then it is hardly a good enough ideal at which to aim. People need something more than this to work towards if they are to contribute to society and grow in maturity.

We face more obviously than most the universal problem of coming to terms with the fact of man's individuality and loneliness. The disabled person's 'strangeness' can manifest and symbolise all differences between human beings and demonstrate the unimportance of these differences compared to what we have in common.

The fourth challenging aspect of our situation follows inevitably from our being different. Disabled people often meet prejudice which expresses itself in discrimination and even oppression. Whatever we do people put it down to our being disabled. You may produce the most logical and persuasive arguments only to have them dismissed as products of our 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 that 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 they tell themselves that you can't really help having these ideas, poor thing.

In the hospitals and homes I have lived in one rarely sees any physical cruelty. But 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 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. In the wider community employers turn away qualified and competent workers simply because they are disabled. Restaurants and clubs give excuses for refusing our custom. Landladies reject disabled lodgers. Parents and relations fight the marriage of a cripple into their family.

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. Contact with us throws up in people's faces the fact of sickness and death in the world. People do not want to acknowledge what disability affirms – that life is tragic and that we shall all soon be dead. Closely associated with death and dark is the idea of an evil body and mind and a warped personality. Disabled people find that the common assumption of good health often carries with it undertones of a moral failure on our part. 'If only you had enough will-power ...'. Sometimes people are trying to reassure themselves that they are 'saved', justified, in a state of grace – 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. Such attitudes, whether in ourselves or others, have to be rooted out.

Nowadays many disabled people will have nothing to do with resignation as it used to be understood. 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.

## Disability and the Helper Helped Relationship: An Historical View

Vic Finkelstein

(Finkelstein, V. (1981) 'Disability and the helper helped relationship: an historical view', in A. Brechin, P. Liddiard and J. Swain (eds), *Handicap in a Social World*. Sevenoaks: Hodder and Stoughton. Abridged by Sally French.)

In this short essay attempts have been made to draw attention to a long neglected area of study: the historical origins of the relationship between disabled people and those who may work with them in a helping role. For convenience the discussion is centred around the disablement of those who have physical impairments although it applies equally to all disabled people. It is hoped that this essay will encourage practitioners to take a more positive attitude towards supporting physically impaired people.

There can be no doubt that over the last two decades there has been a radical improvement in the situation of disabled people in the United Kingdom. Twenty years ago few disabled people were to be seen in public. Probably the most significant measure of this changing and improving situation is the number of physically impaired people who have come forward to express their views and describe their *problems*. It is this trend which is particularly significant in the history of disability and in the relationship between helpers and helped.

Traditionally disabled people have been viewed as passive, unable to cope with normal social relations and dependent on others. The professions came into being with this assumption. 'Disabled people cannot do things' goes the idea 'and therefore we intervene to help'. Central to this idea is the notion that disabled people possess the 'problems'.

Now as disabled people have become more active in defining the 'problem' the traditional helper/helped relationship has come under strain. The suggestion is that in addition to their physical problems disabled people are placed in an oppressive relation to able-bodied people. This is particularly so when as a result of physical impairment they are assumed to be socially passive, inadequate and helpless. Since some of these assumptions underlie the evolution of the professions it has become imperative that traditional restrictive professional practice give way to a new helper/helped relationship. To do this it is necessary to take another look at the assumptions handed down to us by history and, until recently, only interpreted through the eyes of active able-bodied helpers.

## Phase 1

It is convenient to take our starting point with the emergence of the British capitalist system. In its earliest period, prior to the Industrial Revolution, the population was overwhelmingly rural with production essentially agricultural with limited craft production. In these conditions 'cripples' can be assumed to have lived not very differently to the cripples under feudalism. In the small communities of early capitalism everyone knew each other and had a relatively fixed social status with its attendant family and social obligations. Those who survived severe physical impairments would have lived as cripples within their communities. It is this proximity between able-bodied and disabled people which explains the ease with which writers could include crippled characters within the literature when writing about the common people. Conditions of life were extremely harsh for cripples, but in a context where life was harsh for all the common people.

Apart from performing domestic duties for their families cripples unable to perform agricultural work could have supplemented the family income by spinning and weaving. The work was carried out in their home and cripples had no need to seek employment beyond the family. However, the rural population was being increasingly pressed by the new capitalist market forces and when families could no longer cope the crippled members would have been most vulnerable and liable to turn to begging and church protection in special poor houses. Market forces soon favoured machinery which was more efficient and able to produce cheaper more plentiful woven material. Those working larger looms would more likely survive and cripples would have had greater difficulty working such equipment.

The physically impaired people living in early capitalism were just as crippled by capitalist production as they were by the physical condition of their bodies. It took the Industrial Revolution to give the machinery of production the decisive push which removed crippled people from social intercourse and transformed them into disabled people.

## Phase 2

By the late eighteenth century, highly complex mechanical devices were in use. The size of the equipment necessitated special buildings and the increasing need for workers to travel to their place of employment. At this time, the manufacture of machinery became an important economic development. Machines were for use by average human beings and workers could not have any impairment which would prevent him or her from operating the machine. Thus production for profit undermined the position of physically impaired people within the family and the community.

Unemployed workers mingled with unemployable disabled people in the growing towns. The need to control population mobility became necessary as well as the need to control civil discontent among those out of work. So it was that the next step was taken and civil authorities began building special secure places for disabled people and others who had no permanent home or source of income, and staffed these places with wardens and attendants.

In a climate of great productive activity those who did not work were regarded with abhorrence and held to be responsible for their poverty and afflictions. But the work ethic made it necessary to distinguish between those who were able-bodied but did not work and those who were physically impaired. The latter were to be accepted as rightful recipients of charity and the former as indolent wasters to be hounded and punished for their sins. Thus the final segregation process occurred which set disabled people apart from all others. Even in unemployability physically impaired people were to be removed from their fellow citizens. By the end of the 1880s and into the twentieth century it had come to be accepted that disabled people ought to be 'protected' by being placed in large institutions or, when families refused to abandon their members, to be hidden out of sight. The only source of income for

the disabled population was charity. Following the Second World War there was a tremendous development of professionalisms and an isolated disabled population available for intensive treatment.

There have always been a few physically impaired people who managed to avoid the disabling pressures of the social system and find a place within the society where they have achieved recognition as fellow human beings. The movement of this group into the community, however, has confronted them with the experience of disability as a form of social discrimination and oppression. The successful disabled integrators have found that society, unaccustomed by their presence for centuries, has designed a world which does not recognise their existence. Such people have been forced to protest, first individually and then collectively about their social situation. This protest has not been confined to the material world of buildings and streets but includes a rejection of the now well established view that disability means passivity in organising one's own life.

Centuries of isolation have been followed by help to counteract this situation and disabled people have begun articulating their own interpretations of their social situation as well as defining the roles and limitations of the professional and lay workers. It is clear that professional practice which grew up on the basis of the social exclusion of physically impaired people led professionals into a set of practices which has now become a barrier to further development of their client group. What should be clear from the above historical sketch is that it is not professional practice, as such, which impedes the flow of disabled people back into the community but that aspect of their relationship which places them in an active controlling role over a passive patient or client.

### Phase 3

It will be clear that we have only started entering the new phase whereby the helper/helped relationship will become reformed into one of equality. Exactly what the requirements are lies in the future but it is clear that any future relationship between physically impaired people and those who help them will have to encourage the utmost activity of the client in the decision-making process and access to all records, plans and planning meetings will be necessary. If disability was a social imposition of physically impaired people, the reintegration of disabled people will not only remove their disabilities but introduce a new era of cooperative work between helpers and helped.