Disability Studies:

Past, Present and Future

Edited by

Len Barton
And Mike Oliver

The Disability Press

Leeds

The Disability Press
The Disability Research Unit
The School of Sociology & Social Policy
The University of Leeds
Leeds LS2 9JT

© The Disability Press 1997/Mike Oliver and Len Barton, selection and editorial matter; individual chapters in Section One, the Contributors; articles in Sections Two and Three, Carfax Publishing, PO Box 25, Abingdon, Oxfordshire, OX14 3UE, UK

Output from disk supplied and printed by University Print Services, a division of Media Services at Leeds.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic or otherwise, without the prior written permission of the copyright holders.

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloguing in Publication Data
A catalogue record of this book has been requested.

ISBN 0 9528450 1 6

Contents

Acknowledgements

The Disability Press

Contributors

Introduction. The Birth of Disability Studies

Part One

1 A Legacy of Oppression: A History of Disability in Western Culture
Colin Barnes

2 The Limits of Classical Social Theory in the Analysis and Transformation of Disablement – (Can this really be the end; to be stuck inside of Mobile with the Memphis Blues again>)
Paul Abberley

3 From Normalisation to Where
Anne Louise Chappell

4 Including People with Learning Difficulties: Theory and Practice
Jan Walmsley

5 'Growing Pains' Disability Politics – The journey explained and described
Jane Campbell

6 Independent, Proud and Special: Celebrating our Differences
Jenny Corbett

7 When Myths Masquerade as Science: Disability Research from an Equality-Rights Perspective
Marcia H. Rioux

Part Two

8 Personal Trouble or Public Issue
Anne Borsay

9 The Politics of Special Educational Needs
Len Barton

10 The Concept of Oppression and the Development of a Social Theory of Disability
Paul Abberley

11 Stars are not Born: an interpretive approach to the politics of disability
Helen Liggett

12 The Politics of Disability: A New Approach
Mike Oliver and Gerry Zarb

13 Cultural Representation of Disabled People: dustbins for disavowal?
Tom Shakespeare

Part Three

14 Disability and the Myth of the Independent Researcher
Colin Barnes

15 Disability and the Myth of the Independent Researcher: a reply
Mike Bury

16 Rules of Engagement: changing disability research
Tom Shakespeare

17 Fighting Two Different Battles: unity is preferable to enmity
Ayesha Vernon

18 Defending the Social Model
Tom Shakespeare and Nicholas Watson

19 A reply to Tom Shakespeare and Nicholas Watson
Ruth Pinder

20 Integrating Models of Disability: a reply to Tom Shakespeare and Nicholas Watson
Marie Johnston

(Note: These chapters can be accessed via the Disability Archive UK either by clicking in the name of the author or the title of the Chapter).

Acknowledgements

We would like to express our thanks to all the members of the editorial board and contributors who over the years have enabled the Journal to establish and maintain its high international reputation.

We are particularly grateful to Colin Barnes and the students on the Disability Studies course at the University of Leeds, for their helpful suggestions concerning what we should publish in sections 2 and 3 of this book. Of course, we remain solely responsible for the final decision over the published articles.

We are grateful to Carfax Publishing Company for their agreement to publish the past papers from the Journal Disability and Society (formerly, Disability, Handicap and Society).

The Disability Press

The Disability Press seeks to provide an alternative outlet for work in the field of disability studies. The Disability Press acknowledges and draws inspiration from the work of all those countless disabled individuals and their allies who have, over the years, struggled to put this particular issue on to the political agenda. Its establishment is a testament to the growing recognition of 'disability' as an equal opportunities and human rights issue within the social sciences.

Funding for this second volume from the Disability Press has been provided by the Disability Research Unit. The editors also wish to record their thanks for the support and encouragement of the School of Sociology and Social Policy at the University of Leeds.

Contributors

Paul Abberley
1 Rew Lea Cottages,
Rew Road
ASHBURTON,
Devon TQ13 7EL
UK

Colin Barnes
The Disability Research Unit
The School of Sociology & Social Policy
University of Leeds
Leeds LS2 9JT
UK

Len Barton
Division of Education
University of Sheffield
388 Glossop Road
SHEFFIELD S10 2JA
UK

Anne Borsay
Department of History
University of Wales Lampeter
LAMPETER
Dyfed, SA48 7ED
UK

Mike Bury
Department of Social Policy and Social Science
Royal Holloway
University of London
EGHAM
Surrey TW20 0EX
UK

Jane Campbell
7 Holmwood House
South Place
Alpha Road
SURBITON
Surrey
KT5 8TB
UK

Anne Chappell
Buckinghamshire College
Faculty of Applied Social Sciences
Queen Alexandra Road
HIGH WYCOMBE
Bucks HP11 2IZ
UK

Jenny Corbett
University of London
Institute of Education
Department of Psychology and Special Needs
25 Woburn Square
LONDON WC1H 0AA
UK

Marie Johnston
School of Psychology
University of St. Andrews
FIFE
KY16 9JU
Scotland
UK

Helen Liggett
Department of Planning
Public Policy and Management
University of Oregon
Eugene
OREGON 97403
USA

Mike Oliver
Department of Sociology
University of Greenwich
Bronte Building
Avery Hill Road
Southwood Site, Eltham
LONDON SE9 2UG
UK

Ruth Pinder
CSHSD
Department of Human Sciences
Brunel: The University of West London
UXBRIDGE
Middlesex UB8 3PH
UK

Marcia Rioux
Roeher Institute
Kinsmen Building
York University
4700 Keele Street
North York
ONTARIO M3J 1P3
Canada

Tom Shakespeare
University of Leeds
Disability Research Unit
School of Sociology & Social Policy
Leeds LS2 9JT
UK

Ayesha Vernon
Social Policy Research Unit
University of York
YORK
YO1 5DD
UK

Jan Walmsley
The Open University
School of Health & Social Welfare
Walton Hall
MILTON KEYNES
MK7 6AA
UK

Nicholas Watson
Department of Nursing Studies
University of Edinburgh
40 George Square
EDINBURGH
EH8 9LL
UK

Gerry Zarb
Policy Studies Institute
100 Park Village East
LONDON
NW1 3SR
UK

INTRODUCTION

The Birth of Disability Studies

Twenty years ago there was no such thing as disability studies. However there were a few stirrings of interest within the academic world. Disabled people were beginning to politicise themselves around issues such as their poverty and incarceration in residential establishments. They were also beginning to write about themselves in ways which transcended the usual autobiographical `triumph over tragedy' accounts which were and still are common.

Partly as an attempt to capture this newly emerging consciousness and to move beyond the dominance of psychological and medical discourses on disability, the Open University produced a new course titled "The Handicapped Person in the Community" as part of its undergraduate programme in the 1970s. This proved to be enormously popular and subsequently the University of Kent introduced the first masters programme in what later came to be called disability studies.

Following on from these small beginnings and the steady and ever growing stream of writings emerging from disabled people themselves, disability studies began to find its way onto the academic curriculum at both undergraduate and postgraduate levels as well as professional training courses of all kinds. There was no academic journal to support these developments and so in 1986 Disability and Society was first published, initially under the title Disability, Handicap and Society.

THE HISTORICAL CONTEXT

Two major motivations were particularly significant in contributing to the creation of this Journal. On the one hand, there was a powerful desire to provide an alternative forum for the generation of ideas and the encouragement of dialogue and debate. This included establishing a serious and sustained critique of the medical model of disability which legitimated individualised and personal tragedy perspectives. On the other hand, was the intention to create a journal that would endeavour to develop a balance between academic and non-academic needs. This would cover, for example, issues of language, values and interests.

It was essential therefore, that disabled people who had some experience of research and writing were clearly represented on the editorial board.

This was particularly important with regard to the small group of Executive Editors who play a major role in developing policy and monitoring the various aspects of the Journal's profile. Currently there are six members of the Executive Editors, four of whom are disabled academics.

One of the significant and largely unexpected growths of the Journal has been its gradual spread to international markets. Currently we have subscribers from 50 countries and we are increasingly publishing articles from people in a range of different countries. This comparative aspect of the Journal's profile is providing a much needed stimulus which is both informative and challenging in terms of new ways of thinking, different sets of presuppositions, questions and interpretations. Points of commonalty and difference are evident within a more general appreciation of the complexity of the issues involved both at the policy and practice levels of activity.

A journal reflects the interests and development of its editors. One illustration of this concerns that of language. Some of the earlier publications did contain disabilist language. This became an increasingly serious issue which resulted in the editorial board unanimously agreeing in 1993 to changing the name of the Journal and removing `Handicap' from the title. An editorial statement (Vol. 8, No. 2, 1993) was published on the question of language. It was intended to be both a public declaration of where we had now come to in our collective thinking and development and would also be helpful to intending authors when producing their articles. Another aspect of development was the decision in 1988 to include a Current Issues section in the Journal. This was related to our intention to provide an outlet within the Journal for a range of styles of presentation and a means of encouraging controversial ideas. The initial Policy Statement reflects these concerns.

A particularly successful innovation was the introduction of Special Issues of the Journal. These covered key themes and were intended to offer both an indication of the existing ideas and understanding available as well as provide new insights, interpretations and questions for consideration. Special Issues have covered such topics as: `Researching Disability' Vol. 7, No. 2, 1992, `Representation and Disabled People' Vol. 9, No. 3, 1994, and `Disability, Development in the Changing World' Vol. 11, No. 4, 1996.

Different Review Editors have been responsible for the development and improvement of the Reviews Section of the Journal. The intention is to cover a

range of literature and offer different forms of review some of which are brief and others of a much more detailed examination.

We believe that the Journal has now achieved a degree of international reputation that places it at the forefront of developing ideas and establishing connections between disabled and non-disabled people in many societies who are involved in the identification and removal of the barriers of oppression including forms of impairment-led thinking and practice. Past and present editors are to be thanked for their efforts and support in this process of development.

On reflection we now look forward with optimism and a desire to see the quality and influence of the Journal increase beyond that of its first ten years of publication.

TEN YEARS ON

The idea for this book emerged out of the conference held in Ashford, Kent, in September 1996 to celebrate the first ten years of the Journal. The papers given and the speakers chosen were designed to reflect some (though not all) of the issues and themes that the Journal has been instrumental in both raising and developing.

This book is an attempt to make the original papers available to a wider audience (Part One), to include some of the important papers published in the Journal over these years (Part Two) and to offer insights into some of the controversies that have emerged (Part Three).

PART ONE

The theme of culture is one that has been discussed regularly throughout the Journal. Barnes in his contribution considers the importance of culture in shaping social attitudes to disabled people in pre-industrial societies and also suggests that contemporary attitudes can only be properly understood by reference to these cultural antecedents.

The development of theory has been an integral part of the history of the Journal. Abberley made a major contribution in his seminal discussion of oppression and here he argues that a truly liberatory theory of disablement needs to transcend the Marxism on which much current theory is based. He suggests that impairment will remain problematic in societies where notions of humanity and value ultimately depend on labour.

Other theoretical debates within the Journal have focused on the issue of normalisation. In this section Chappell provides a review and commentary on this developing critique as well as attempting to pose some difficult questions for disability theory; notably concerning the current exclusion and future inclusion of issues of learning difficulty in the mainstream of these debates. Walmsley, in her chapter, takes up some of these issues and describes a project which attempts to involve people with learning difficulties as equal partners. She considers the potential and limitations of such collaboration before finally raising some more general questions for both theory and practice. Disabled people's attempts to transform disability from a medical to a political issue have also featured prominently throughout the life of the Journal. Campbell in her chapter reviews this and discusses the ways in which the emerging collective consciousness of disabled people has developed into a full-blown social movement in Britain at least

An essential element in the politicisation of disability has been the recognition that the personal is political. Corbett uses this theme to discuss a series of papers she has written for the Journal over the years, documenting her changing understanding of issues of independence, difference and empowerment and showing how they made a contribution to the transformation of her own consciousness.

The rise of disability politics has had an important impact on research and this has been stimulated by and reflected in the Journal. Rioux, in the final chapter in this section, provides an overview of this, distinguishing between what she calls the individual and social pathology models of research. She reminds researchers of their ethical and political obligations as well as their scientific ones and concludes on a positive note in suggesting that, the emerging disability movement world-wide will force researchers to accept these obligations.

PART TWO

Selecting a few papers from the last ten years when the Journal has published more than 200 has been no easy task. We have tried to use the following criteria; (i) the paper has made an original contribution to disability studies (ii) it fits in with the themes and issues discussed in Section 1, and (iii) the popularity of the papers amongst the readership. This is not to imply that the papers not included are deficient in one or more of these ways but the process of selection has been an extremely difficult one.

The papers by Borsay and Barton were important in that they attempted to apply newly emerging disability perspectives to social policy and education respectively. Borsay takes the social model of disability as her organising theme

and Barton uses his own personal experience to inform debates about special, and indeed by implication, all forms of education.

Abberley and Liggett, in their papers made key contributions to the development of disability theory; the former drawing upon marxist, feminist and anti-racist perspectives and the latter utilising post-modernise perspectives and particularly the work of Foucault.

The next two papers look at the issue of politics. Oliver and Zarb provide critique of existing models of political representation and suggest that new social movement theory is a better way of conceptualising disability politics Shakespeare provides a similar critique of cultural representations of disable(people and argues that the negative imagery which predominates has to be challenged by developing a cultural politics of disability.

PART THREE

The Current Issues section posed similar problems in that since its inception it has served as a vehicle for debating a wide range of issues, for allowing disabled people a voice on issues that are important to them, for incorporating pieces from across the world and much more. Our selections here are chosen mainly to fit in with issues raised throughout the rest of the book in order to give it an overall coherence.

The first three papers appeared side by side and reflect a debate that began at an international conference held at the University of Leeds in 1995. Al three provide differing views on the nature of the research enterprise an(discuss issues that have been of concern throughout the life of the Journal.

INTRODUCTION

The paper by Vernon returns to the theme of oppression originally raised by Abberley and discussed subsequently by Stuart and Morris in the Special Edition on disability research already referred to.

The final three papers again appeared side by side and provide some of the latest thinking on debates around the social model of disability currently occurring both amongst disabled people themselves and within academic circles.

We hope this book will be widely read and provide a stimulus for reflection and debate and thereby contribute to the development of disability studies as a serious field of study and research.