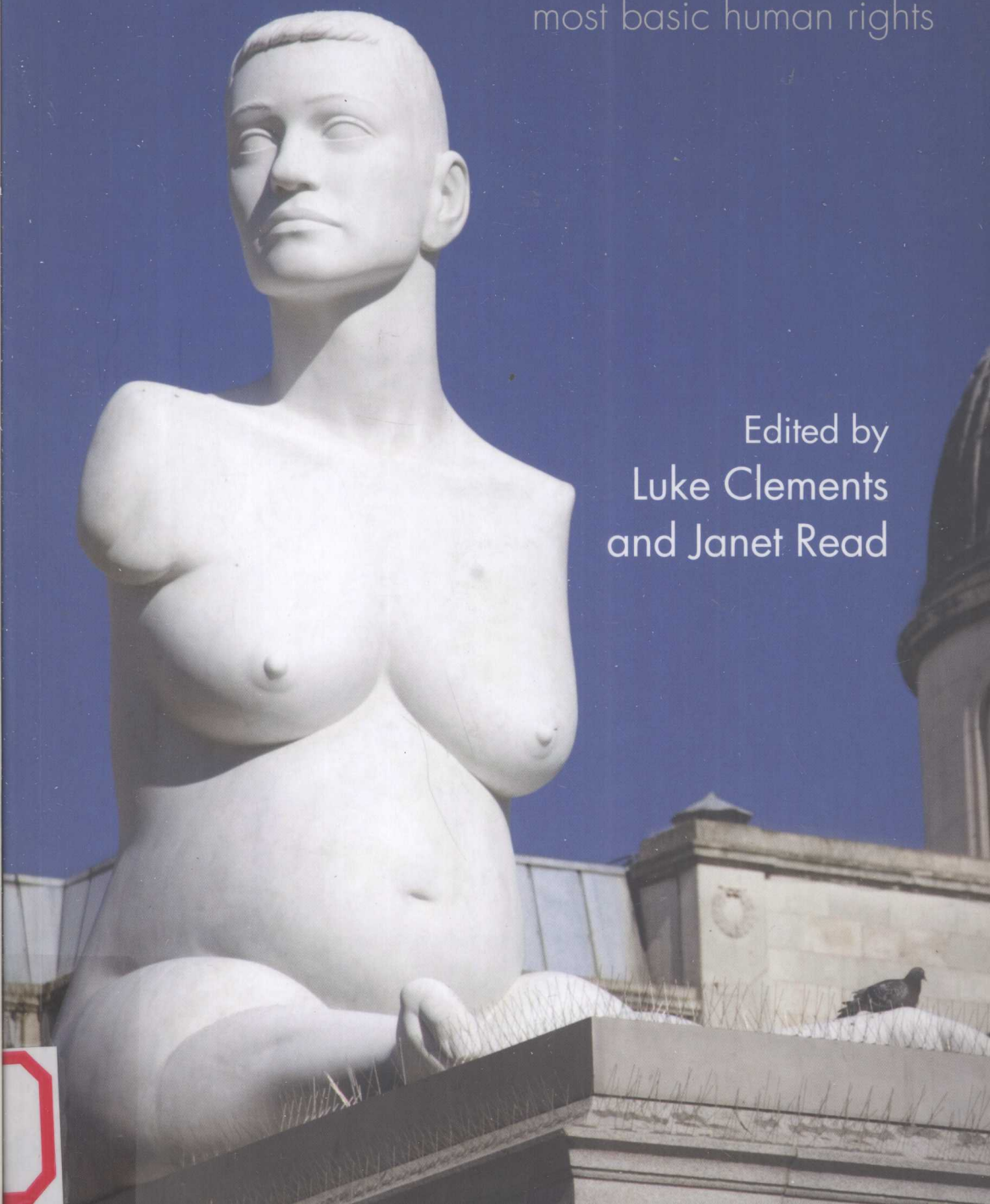


Disabled People and the Right to Life

The protection and violation of disabled people's
most basic human rights

Edited by
Luke Clements
and Janet Read



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Disabled People and the Right to Life

Disabled People and the Right to Life looks at disabled people's right to life in its wider sense, discussing the right to a life that is not intolerable, a life worth living. This volume uses a human rights perspective to explore debates and challenges around what this means for disabled people.

Human rights has increasingly come to be seen as a significant framework both to aid understanding of the experiences of those who face oppression and to underpin social, legal and political measures to counter it. The most fundamental of human rights is the right to life – a right which is enshrined in international treaties and covenants as well as in domestic law in many countries, but which cannot be taken for granted by disabled people. With perspectives from both developed and developing countries, the book chronicles attitudes and practices, critically analyses changes and explores the extent to which such changes have been driven by social as well as legal developments. Chapters explore issues such as:

- cost-effectiveness analysis and preferences
- disability rights and resuscitation
- assisted dying versus assisted living
- access to care
- the selective non-treatment of disabled babies and young children.

The distinguished panel of contributors includes academics, practitioners, public officials and activists. This truly interdisciplinary book will be of interest to students and researchers of disability, law, social policy and human rights.

Luke Clements is a professor in law at Cardiff University Law School, Wales, and a practising solicitor.

Janet Read is an associate professor and reader at the School of Health and Social Studies, University of Warwick, UK.

**This book is dedicated to the memory of Katy Sunman,
April 1980 to April 2005.**

**Her zest for life changed and enhanced the lives of all
who knew her.**

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Preface

Luke Clements and Janet Read

This collection of essays is concerned with disabled people's right to life in its wider sense: the right not only to life, but to a life that is not intolerable, a life worth living and all that that connotes. The distinguished contributing authors have been asked to consider this question from a human rights perspective. In relation to the developed and developing world, such an approach has increasingly come to be seen as a significant framework both to aid understanding of the experiences of those who face oppression and to underpin social, legal and political measures to counter it. The concept of human rights is also increasingly being used to provide a unifying and defining paradigm for research on a wide range of topics across the boundaries of different academic disciplines. While the most basic of human rights, the right to life, is enshrined in international treaties and covenants as well as in domestic law in many countries, there is substantial evidence that for disabled people, this most fundamental of human rights can by no means be taken for granted on the same terms as their non-disabled peers. The law is seen as one element of a dynamic set of social, cultural and historical processes impacting on the human rights of disabled people. The book aims to chronicle attitudes and practices, to critically analyse changes that have occurred and to explore the extent to which such changes have been driven by social as well as legal developments.

This preliminary note must, perforce, draw attention to omissions and limitations. Drawing a boundary round the topic and deciding what should be included and what should be left out has not been easy. There is a danger that we shall inevitably appear to offer a partial account or to give only glancing attention to things that appear crucial to individuals or groups for whom the right to life signifies more than an academic debate. Inevitably, too, there are accounts and analyses of experiences that we desperately wished to see documented in the book but which we were unsuccessful in commissioning: an omission, therefore, does not necessarily indicate that an issue is regarded as less important.

It is perhaps inevitable that a book of this nature has 'Western tendencies' since the idea of a legally enforceable right to life for disabled people is more likely to find expression in the literature of developed nations.

Aware of this danger, we have endeavoured to include contributions from as wide a range of countries as possible. In this respect we have been only partially successful and in relation to Africa we have (despite our best efforts) failed. It is of particular concern that the South African experience is absent given its unique situation in history, emerging from the horrors of apartheid and the AIDS disaster. This allied to its relatively enlightened government and an inspirational constitutional court would make for an extraordinary story: a story that must be told – hopefully in a companion publication.

While we took a decision that the prevention or cure of impairment is beyond the scope of this book, it is important to recognize that this has been and continues to be an important area of debate within disability studies and disability rights activism. In many respects, the issues it raises are of course pertinent to, and intersect with, disabled people's right to life.

The essays in this volume represent the work of activists, academics and those involved in some form of practice in relation to disabled people and disability rights. We regard ourselves as fortunate to have worked with those who have made and continue to make such a significant contribution to this field. The contributors were invited to adopt a broadly sociolegal approach and to explore the forces and circumstances in different national contexts which have promoted disabled people's right to life or legitimated its violation. We also asked them to approach the question of disabled people's right to life from the perspectives they considered to be of most importance and relevance to their experience and context. As a consequence, they have offered a broad-ranging, eclectic and stimulating series of essays centring on a number of key themes. The right not to be arbitrarily killed is, of course, crucial and fundamental but it is only one element of right to life issues. Others include the right to *a* life: the right to be valued, to be treated with respect and dignity and to expect the basic life chances, autonomy, aspirations, protections and sustenance that others take for granted.

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1 Introduction

Life, disability and the pursuit of human rights

Luke Clements and Janet Read

Introduction

On 13 December 2006 the General Assembly adopted the United Nations Convention on the Rights of Persons with Disabilities. It affirms unequivocally disabled people's right to life. The previous month however, on 6 November, the *Sun*, a British tabloid newspaper, under the headline 'Kill disabled tots, say top docs', reported that the Royal College of Obstetricians and Gynaecologists had asked for a debate on the possibility of introducing active euthanasia in some cases. The *Sun* reported that such practices were intended to spare parents the emotional burden and financial hardship of bringing up sick children. The newspaper invited its readers to contribute to the debate: 'Have your say. Do you think disabled babies should be killed? Tell us what you think.' (*Sun Online*, Monday, 6 November, 2006, p.1). It is difficult to imagine a newspaper inviting its readership to vote on whether any other group of UK citizens should be killed or allowed to live. The fact that the *Sun* saw it as acceptable to do so in relation to disabled infants, together with the issues it highlighted as germane to the debate, offers a telling reminder of the reasons why many disabled people feel that little can be taken for granted in relation to the valuations placed on their lives.

As Shakespeare (2006) indicates, end-of-life issues for disabled children and adults have been given increased public and mass media attention in Western countries in recent years. As well as the issue of active euthanasia in relation to newborn children, there have been debates about the withholding or withdrawing of treatments for babies and for adults for whom such interventions are judged to be futile and too invasive and painful. In addition, there have been proposed changes to the law in relation to physician-assisted suicide. Discussions on matters of principle have often been linked to landmark legal cases; recent examples include: in the US, concerning the withdrawal of a feeding tube from Theresa Marie Schiavo (Lazzarini *et al.* 2006); in Australia the withdrawal of life support (Messiha 2004); in the UK, Oliver Leslie Burke's challenge to maintain life-prolonging treatment (Coggon 2006); before the European Court of Human

Rights, the right to assisted suicide (*Pretty v. UK* 2002) and the failure to make available life-sustaining treatments in South Africa (*Minister of Health and others v. Treatment Action Campaign and others* 2002) and Ecuador (*Mendoza and Ors v. Ministry of Public Health* 2004).

While some end-of-life matters are irrevocably bound up with advanced medicine in developed countries, this is not the key issue for many disabled children and adults across the world who face appalling deprivations without recourse even to the most basic healthcare (see, for example, Ghai 2001). A limited but growing and important literature on disabled children and adults in developing countries indicates the extent to which the lives of many are constantly placed in jeopardy (Priestley 2001a).

This chapter employs a sociolegal approach to explore disabled people's human rights and, in particular, their right to life. In addition to human rights law, our analysis is heavily influenced by a wide-ranging disability rights literature, and we have tried to ensure that the experiences, perspectives and rights of disabled people, insofar as they are known, are the focus of this work. In this paper, we not only explore those things that directly threaten the lives of disabled children and adults and in some cases, arbitrarily bring them to an end, we also consider some of the processes and circumstances which in one way or another, place life in jeopardy. The withholding or restricting of resources that promote and sustain life and health may have a devastating impact on life and life chances. The ways that disabled people are seen or not seen and the degree to which they are subject to carelessness, neglect, disregard or ignorance, all crucially lay the groundwork for and, in turn, may be used to legitimate violations of their right to life.

Understanding disability and the valuation of disabled lives

The ways we define and theorize disability crucially determine how we approach matters bound up with it, including end-of-life issues. But as Asch (2001:300) observes, terms such as 'health', 'normality', 'impairment' and 'disability' are highly contested: 'Their meanings are not clear, objective, and universal across time and space and are contentious even for contemporaries in the same culture, profession and field'.

Until the late 1970s and early 1980s, in published work, the most influential and dominant ways of describing and defining disability were shaped by a Western biomedical paradigm. As Imrie (2004:289) argues, this largely reflected the medical profession's view of the impaired body as an 'object of scientific interest, classification and medical intervention'. The influence of such discourses with their primary focus on impairment, disorder and defect, together with their assumed consequences, went far beyond the profession of medicine. In the quarter of a century following the Second World War, the Western literature associated with all professions with responsibilities towards disabled children and adults had a marked tendency to characterize them, their personal relationships and their wider

social functioning as inherently and inevitably pathological. Disabled people and those close to them were frequently problematized and there was little appreciation that disabled people might experience or aspire to things that their non-disabled peers took for granted (Philp and Duckworth 1982; Thomas 1982; Read 2000). It was considered possible by some to predict with accuracy the quality of life that disabled people and those close to them might expect, solely with reference to the type and degree of impairment diagnosed in infancy (Read and Clements this volume). Such predictions could form the basis for crucial treatment decisions with implications for the saving or curtailing of life itself (see, for example, Lorber 1975).

Biomedical understandings of disability have undoubtedly remained highly influential (Asch 2001) but across the past three decades, they have been challenged and shaped by social theories of disability. While a range of work in the late 1970s and 1980s began to acknowledge the social dimensions of disability (e.g. Blaxter 1975; WHO 1980), the major theoretical and ideological corrective to established understandings of disability came from a growing body of politically engaged scholarship which gained ground through the 1980s and 1990s, initially in North America and Western Europe. This wide-ranging work, sometimes identified as 'disability studies', drew variously on social science and the law to reframe disabled people's experience and progress their rights (see, for example, Gliedman and Roth 1980; Fine and Asch 1988; Oliver 1990; Barnes 1991; Bynoe *et al.* 1991; Morris 1991 and 1998; UPIAS 1976). Many of the academics involved were themselves disabled and the interrelationship between the academic endeavour and the political activism of a strengthening disability rights movement was held by some to be a defining feature of the new disability studies (Abberley 1996; Bickenbach *et al.* 1999; Campbell and Oliver 1996).

At the heart of this work lay a central and unifying set of understandings about disability: a conviction, born of experience, that some of the most restricting and debilitating features in the lives of disabled people were not a necessary or inevitable consequence of living with impairment. Rather, it was held that these restrictions were socially and politically constructed and could, therefore, be changed by social and political means. Variants of 'the social model of disability' gained widespread use as an approach to understanding disability. Some differences notwithstanding, there is now, according to Wasserman (2001:225), 'a broad consensus among scholars writing about disability that the limitations associated with impairment are a joint product of biological features, environmental factors and personal goals'. Thus, as a consequence of these developing understandings of disability, it began to be seen as meaningless to consider impairment out of its social context or to use it alone as the primary indicator of present or future life experience, quality of life or life satisfaction.