

BOOK REVIEW

Disability in Australia-Exposing a social apartheid

Janne D Graham

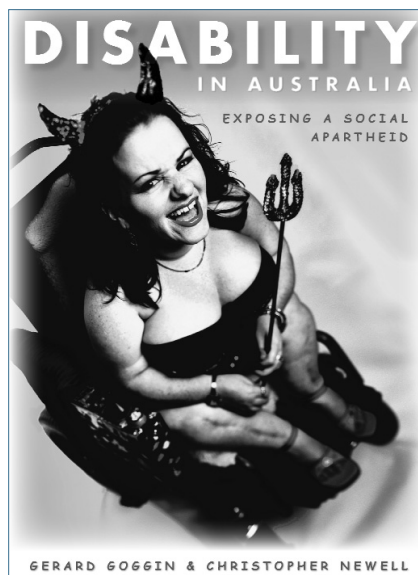
Members of CHF and readers of *The Australian Health Consumer* will be familiar with one of the authors, Christopher Newell, as a long-time CHF Governing Committee member, member of CHF Editorial Subcommittee and long-time activist for health consumer and disability concerns. Some may know his co-author, Gerard Goggin, though I do not. Together they have clearly developed a remarkable writing partnership, of which more later.

It is important for me to declare that this is not a dispassionate review by a disinterested bystander. I read the book with many recollections of my own disability journey and with many memories of the small glimpses I have been privileged to have of Christopher's greater and ongoing journey. Though for all that, I hope it is a useful review.

The story of disability in Australia is told by looking at it through our society and its culture, including its language. By moving our gaze from the individual to a society that engages in 'special' ways with disability we are immediately required to think about power and how it is used: the power of the caring professions, of administrators and bureaucrats, of science, industry, of the media and of our own contradictory concepts.

The book focuses on a series of community settings within which disability is experienced. Firstly, arenas that separate our bodies from the mainstream: health, welfare and disability services; sport and biotechnology. Secondly, arenas that separate us from social and political engagement: where we live and how and where we are heard. Within the latter is a chapter on refugees, which at first sight might seem to be beyond the brief of the text but in fact is not only powerful in its stories but also germane and central to the argument.

What is the argument? It is put in the form of a question: '... whether the continuing oppression of people with disabilities, the fundamental injustice, exclusion and marginalisation we daily experience, is a form of "apartheid" ...' (p18). The case is made at three levels. The first is the one with which readers of this journal will be familiar, the stories of the day-to-



DISABILITY IN AUSTRALIA
Exposing a social apartheid

Gerard Goggin and Christopher Newell
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day experiences of people with a disability and the history that put them into context. The second level is one that addresses the structural barriers inherent in these experiences, again familiar to those of us who work from the stories to policy development, drawing the general from the particular. Familiarity should not imply that the writing lacks interest at these levels. These stories, put in new ways, still have the power to shock and challenge.

We are asked, for instance, to recall the large institutions that isolated and made disability less visible. Then there was the movement to 'de-institutionalise' and to 'valorise'. What changed? The big buildings have been converted to other uses, with barely an acknowledgement of the lives they contained. And so many people with disabilities today continue to be isolated, either in nursing homes for the aged or in small group homes often with unskilled staff, operated still on institutional lines, and with little connection with the surrounding neighbourhood.

But there is another (deeper?) layer of analysis. The discussion looks at the meaning our bodies have for ourselves and each other. It looks at the language we and others use both in describing disability and in using terms related to disability to characterise other understandings. It draws on a post-modern sociological perspective, useful, but sometimes difficult because old words take on new meanings and new words have to be developed to describe new understandings.

Sociological analysis also has a habit of setting our preconceived notions on their head. One finds oneself saying: 'yes, but ...'. Fortunately, the authors often stop at these points and help us through. Often these questions come from our own culturally defined view of disability, at least the disability of others, as a medical condition to be fixed, a deficit to be supplemented, or a tragedy to be ameliorated.

Take one example. Pre-lingually deaf people often regard themselves as a cultural minority separated by language (in Australia: AUSLAN) rather than as people with a disability. There is therefore a genuine question to be asked about the role of cochlear ear implants in

managing the medical condition of deafness in young children. And certainly a question to be asked about the level of resources put into this technology compared with that available for education and resources for AUSLAN teaching and interpreting. In the United States, we are told, a pre-lingually deaf couple using IVF sought court permission to select an embryo with the deafness gene and was refused. In Australia, a hearing couple sought to select an embryo without the deafness gene and was granted permission. What is it in our culture that finds one type of designer baby more acceptable than another?

The authors do not tell us in this, or in their other analyses, what ought to be the case. They do set us asking who is defining disability and what meaning and use does it have for society. They do question where people with disabilities are in the moral, ethical, legal and policy discussions that do or should be occurring. They do wonder if we can have a just or fair society (a civil society is today's current phrase) when, on the one hand disability is used as a justification for special care, for research, for charity, while on the other hand people with disabilities are excluded and marginalised from the society.

This book has disturbed me. It has exposed several of my previously held values as inconsistent and open to challenge. As a person with an adult acquired experience of disability I still, like the community in general and as our language portrays, see my impairments as a loss. The authors are kind to me, even in this:

For those born with an impairment or condition their lived experience and meaning of disability is an integral part of their life, whereas for many with acquired disability it becomes a tragedy. These experiences, and the meaning people make of them, are very much part of the larger cultural and social frameworks ... that add great complexity and richness to how people with disabilities understand the world, and how we all understand our abilities, capacities and identities. (p116)

Readers are offered visions of a better future throughout the text, visions easy to embrace. The authors' recommendations for getting there are less convincing. This is not surprising. The conversations about the book's thesis have to occur first. Those conversations certainly have to involve people with disabilities in all 'our richness and complexity'.

As I write this review the debate about abortion is being rekindled. Politicians Abbott and Andrews have now been joined by the Governor-General in questioning either the availability of abortion or its prevalence. It seems inconceivable these days that the debate will go on for much longer without women's voices being heard—to borrow the authors' phrase 'in all our richness and complexity'. I now see that this is

a debate that also has to be seen through the eyes of people with disabilities because abortion is a mechanism for 'fixing' disability. The Right to Life versus The Right to Choose is a sterile debate. As health consumers and as people with an interest or experience of disability we need to make sure that the relevant voices, our voices, are heard. Too often our organisations have stayed silent in these debates, fearing they will divide our membership. In this case what are the social policies, the cultural pressures and the language, which impact on abortion? What should they be? As this book shows there is an opportunity to conduct critical value debates in new ways.

Back to the authors. The remarkable thing about this collaboration is that the authors are not invisible, silent writers. They are there in the story. They tell us their own experience of separateness from each other as they write. We hear how they are finding their own ways to shared participation in the endeavour. We see how they are testing in their own work their suggestions for ways of creating change available to us all. This makes it unusual as a scholarly study but demonstrates that sound analysis does not depend on silencing the personal. Another rare feature that demonstrates consumer friendliness is that the book is available in CD format by the simple mechanism of sending a tear-out slip from the back of the book.

In his foreword, The Hon Justice Michael Kirby says: '[the] book will find its place in the academic market both for undergraduate and postgraduate study ... ordinary citizens too can read this book, reflect and learn' (p12). I humbly agree. Its price will not be a barrier to libraries but the rest of us may have to put it on our Christmas list or scrounge a copy from our better-off friends (sorry about the royalties, chaps).

From its dramatic cover (a voluptuous wheelie as devil) to its thoughtful conclusion, this book takes the familiar experiences of people with disabilities and turns them into a challenge for the community as a whole.

How and why do we as a society continue to treat people with disability as subhuman; to perpetuate apartheid in a land that embraces egalitarianism as one of its cherished myths. (p211)

Indeed.

Janne Graham is a former Chair of the Consumers' Health Forum of Australia.

Editor's note: Christopher Newell, who is Chair of the Editorial Sub-Committee for The Australian Health Consumer was not involved in the selection of this book or the content of the review