

CHAPTER 1

INTRODUCTION: THE DISABLED FACE OF SOCIETY

*Why would I employ a one-legged man,
when I could employ a two-legged man?*

Australian university professor, c. 1991.¹

We have made some legitimate gains in terms of physical access but the real problem is yet to be fully addressed. Negative attitudes towards people with disabilities are rife in the community. If we are to achieve any sense of true emancipation, we must fight attitudinal barriers to equal participation in all aspects of community life. Nothing is really going to change until we do ... Our lives are governed by legislation. Carers refuse to handle our bodies without the protection of latex ... our bodies remain the property of those who lift, dress and wipe. Women with disabilities continue to be sterilised and when we do reproduce, over one third of our children are removed from our care. Quite often, our pregnancies are terminated against our will. We are raped by institutional staff and yet forbidden to engage in consensual sex. Our finances are managed and our lifestyles are regulated by duty of care.

Kathleen Ball, 2001²

The odds are pretty good that many 'normal' people reading these words will become disabled within twenty or thirty years, and many readers with disabilities will become people with multiple disabilities.

Lennard J. Davis, 1995.³

If we are to believe the headlines, then the solution for Australians with disabilities is just around the corner: the latest medical advance, the miracle found in technology, the funding program which will assuage our collective consciences, better prevention of disability. Why, then, would we need a book about disability in Australia?

After all, in the last twenty years we have built in a lot of curb cuts, installed accessible public toilets, and learnt to speak nicely to the people formerly known as handicapped. What more could be needed? Perhaps the best answer lies in the everyday lives of Australians with disabilities, their families, friends and carers.

Scenes from everyday life

• CASE STUDIES Joan is twenty-nine, a graduate with an obvious disability, a guest at a cocktail party. 'What's wrong with you?' says someone to whom she has just been introduced.

• It had been one of those days. John had survived to the end of a day of furtive glances and whispered asides as people strove to cope with the drooling and their discomfort at his communication disability. He sat in the rain – half an hour, an hour – waiting for the wheelchair taxi that wouldn't come, while so many other so-called normal taxis were hailed by his colleagues, whisking them off home – the end to a perfect day.

• Henry was a man with an intellectual disability, who lived in a large congregate facility. He and others Henry lived with have endured abuse, exploitation of their vulnerability and denial of their human rights over the past twenty to thirty years that they have lived in an institution. Henry's greatest wish was to move into a house of his own. His three goals were to be able to sit on his own verandah, to have a hall table on which to keep his keys, and to be able to walk up the street and watch the lawn bowls. Over the last five years, things have changed, and the new management of the service listened to

Henry's complaints, and agreed with him that he should indeed be able to expect his own place in the community. However, this never became a reality. One Friday in 2001, Henry took issue with the manager of the service, asking her whether or not she was going to 'get me out of here before I conk out'. Five days later he died, angry and frustrated with the service that could not provide him with the support he so much wanted and needed.

- It had all seemed a grand adventure thirty years ago: setting off for the sunny shores of the new Promised Land, migrating in search of a better life. Now, after years of heavy labour working on building sites and in factories, George cannot work because of back pain. He visits Centrelink, fills out forms, and tries to get someone to understand a deep, shameful and yet pressing reality. In the midst of all the jokes about 'bad backs', he does not qualify for government assistance.

- It is the day when tennis star Mark Philippoussis is playing in the final at Wimbledon. The headline of the front page of a Queensland Sunday newspaper has the scoop: 'Scud's brave journey from wheelchair to Wimbledon'.⁴

- 'Superman flies again', reads the newspaper headline. Movie star Christopher Reeve has arrived in Australia, flying first-class, free of charge, in a specially modified Boeing 747, courtesy of an Australian airline, with his entourage. Reeve has been invited to speak about the promise stem cell research holds for 'curing' disability. The same week, Christina also travels with that airline: her wheelchair is damaged; her schedule and lifestyle are severely disrupted. No-one in the media seems interested.

- Jason and Judy live with two friends in a suburban home. Recently they have been spending a lot more time together; they have fallen in love, and want to have a baby. They receive a great deal of well-meaning advice about the pitfalls of pregnancy, childbearing and bringing another child with disability into the world. Being labelled as having intellectual disability seems overwhelming, far more important than their love for each other.

- Putja was three when she was sent to Adelaide for treatment and rehabilitation as a result of poliomyelitis, in the late 1950s. What she cannot understand to this day, is why, when her time in hospital was finished, she was put in the care of a European family in Adelaide,

without any consultation with her family. The family discovered her whereabouts when a friend who lived in Adelaide sent them a photograph cut from a newspaper. Putja's perception was that the father of a white boy in the bed next to her simply wanted to look after her and there was no consultation with her natural, Anangu, family.⁵

- Kate met a nice girl in the café the other day. She would like to get to know her better and send her a text message on her mobile. The problem is that mobile phones have not been designed so that blind people can use them unhindered, for texting and all the other essential functions of life.

- The government proudly launches its new deal for people with disabilities. The Minister enters with her advisors. 'A proud new day in this government's promotion of life options for people with disability,' she exclaims. The selected citizens with disabilities are wheeled out; the photo opportunity begins: 'Could we have one with you standing there, please Minister?'. 'Now with that one over there?'. With meaningful looks at their watches, the Minister's minders move her on.

- A Deaf woman remembers growing up in a small rural town in the 1970s. She attends the local school, where the teachers discourage her from using Australian Sign Language (AUSLAN), and press her to learn to lip-read and use the 'oral' method. Later on, when she uses sign language in school, her teacher throws chalk at her and makes her sit on her hands. Today her Deaf sister-in-law and Deaf brother are the proud parents of a one-day-old baby. Unannounced, nurses and doctors cluster at the bedside, asking if they would like tests immediately to check if the child has a hearing impairment. 'Why?', she responds. ●

Apartheid? ... Australia?

These and so many other experiences are the untold narratives, the unsung, often shameful realities of the everyday lives of those Australians we identify as having disability. Sadly, they reflect taken-for-granted attitudes to the extent that some may not even recognise the devastating values inherent in such daily realities.

Did not we as members of Australian society 'deal' with disability back in 1981, the International Year of Disabled Persons, the year when we supposedly broke down the barriers? Yes, this was a water-

shed for understanding of disability in Australian society; yet a little over twenty years later not much has changed. Whatever the activity or realm of social life, people with disability endure a certain form of apartheid – and one that no-one will name.⁶

Many people with disabilities are isolated from mainstream society. We face discrimination in public and private life. We experience great difficulty finding paid work and advancing our careers. Our bodies, identities and sexualities are controlled by welfare, health and law. We are on the margins of cultural life, under-represented in theatre, film and media industries, rarely portrayed in diverse ways in newspapers, television sit-coms and soaps, and have difficulty gaining access to the internet and new media technologies. And, yes, we still find that lack of wheelchair access is an everyday issue.

The surprising thing concerning the exclusion of people with disabilities in Australia is that such fundamental discrimination and inequality directly affects the lives of millions of people. For example, the latest statistics indicate that nearly twenty per cent of the population has a disability:

In 1998, 3.6 million people in Australia had a disability (19% of the total population). A further 3.1 million had an impairment or long-term condition that did not restrict their everyday activities. Of those with a disability, 87% (3.2 million) experienced specific restrictions in core activities, schooling or employment.⁷

Each of these 3.6 million people has family, friends, lovers, work-mates, colleagues and other associates who live in relationships of interdependence with them. For example, in 1998, over 840 000 children aged 0–17 years (18 per cent of all children) lived with a parent who had a disability.⁸

In this book, we ask whether the continuing oppression of people with disabilities, the fundamental injustice, exclusion and marginalisation we daily experience, is a form of 'apartheid' – an apartheid that knows no name. In borrowing this term, cruelly coined as a shorthand for policies of racism in South Africa, we do not wish to claim that the situation of the oppressed in that country, or others who endure racism, and the enduring inheritance of colonialism and imperialism is the same as that presently facing Australians with disability. Rather, by talking of apartheid, we aim for a jarring of

the unconscious, deeply held and often cherished views and power relations structuring disability in Australia. The experience of apartheid in South Africa was very much about the denial of identity and community. Dehumanisation was central to this, and normalised. It was grounded in and orchestrated across social, cultural, legislative, educational, economic, and legal contexts.⁹

Doubtless many Australians would be surprised, disconcerted, uncomprehending, upset or offended at the idea of contemplating disability as 'apartheid'. Yet there are startling resemblances between the stark racism of apartheid in South Africa and the situation of people with disabilities in Australia. There is a sense in which apartheid does usefully indicate the systematic exclusion, the profound and disturbing oppression and the lack of freedom and equality that Australians with disability experience in the early twenty-first century. Compared with the rest of the Australian population, as Australians with disabilities, we are more likely to live in poverty. We are more likely to be physically, emotionally and sexually abused.¹⁰ We are more likely to be dependent on paid carers to carry out basic tasks. We are more likely to experience difficulty in obtaining education and employment, and more likely to experience difficulty in acquiring affordable accommodation.¹¹ We are more likely to have problems accessing public buildings, basic information in ways we can understand, and public transport. We are less likely to own our own homes, and so it might be a while before we star in home renovation reality television programs like 'The Block' (2003). We are less likely to get married and have children, and often face discrimination in our choice of partners. Women with disabilities face particular disadvantage and marginalisation (the proportion of males and females with a disability is similar although it varies across age groups):

- women with disabilities are less likely to be in paid work than other women; men with disabilities are almost twice as likely to have jobs than women with disabilities;
- women with disabilities are less likely than men with disabilities to receive vocational rehabilitation or entry to labour market programs;
- women with disabilities earn less than their male counterparts.

51 per cent of women with a disability earn less than \$200 per week compared to 36 per cent of men with a disability. Only 16 per cent of women with a disability earn over \$400 per week, compared to 33 per cent of men with a disability;

- women with disabilities are less likely than their male counterparts to receive a senior secondary and/or tertiary education. Only 16 per cent of all women with disabilities are likely to have any secondary education compared to 28 per cent of men with disabilities.¹²

'Apartheid' ('*apart-ness*'), signifies a people set apart: human beings who are regarded as fundamentally and radically other from their kindred people. In South Africa, a division was infamously drawn between places reserved for 'whites', 'coloureds' and 'blacks'. Those identified as 'black' might only be able to swim at 'black'-only beaches; certainly not the beaches set aside for the privileged 'whites'. In Australia, and in other countries, a kind of apartheid exists too, partitioning those who are 'abled-bodied' (at least temporarily so) and those who are 'disabled'. There are special places, practices and accommodations that mark a line not to be crossed between 'normal' and 'disabled'. People with disability have special accommodation, special transport, special access, special income support and even special sporting events. As Baden Offord has suggested:

Apartheid is a force to be reckoned with, an insidious ongoing and entrenched repetition of society's design for itself. Disability, like sexuality, is spatially regulated, corralled, set-apart, divorced, cut from and by the dominant cartographers of normal land. 'Home' becomes a hole.¹³

In proposing the term 'apartheid' to describe the system of exclusion faced by people with disabilities, we are also mindful of the appalling race relations of our own country, where our indigenous peoples are oppressed in so many ways, stemming from the invasion of the continent and their negation as human beings. For us the continuing spiritual, social and political devastation of Aboriginal and Torres Strait Islander peoples associated with a failure to adopt processes of reconciliation and justice making have a significant disability angle. Out of

the practices of colonisation has arisen the situation where in so many ways our indigenous people are subject to much higher rates of disability and early death compared with non-indigenous Australians.

While many may recognise the way that people with disabilities are given, in that damning phrase, 'special treatment', they may feel that it is odd or even obscene to question these practices. For example, how could one possibly question the need to provide people with disabilities with 'special income support'? How could such a 'special' program be seen in any way as a negative? How could it be anything else but a kind and helpful response to those who are deserving of state welfare support by virtue of their disability? We would suggest that there is something else very important at stake here. If we ask why people with disabilities should be in a situation where they may need 'special income support', we can start to unpack the complex power relations and ideologies of disability – summed up in our notions of what is 'natural', 'normal' and even 'nice'. As a starting point, it might be contended that it is only because of our narrow norms of work, productivity and what it is to be a contributing member of society that we create people within whose minds and bodies we locate inability to contribute. Those we are afraid of, who work differently, who work more slowly, who need flexibility, and perhaps even those who require information in different formats, working situations that embrace limited mobility become all too difficult. If we are one of 'these' people, we become those who need special accommodation, special placement, case management, and even training to support workplace peers in how to deal with and manage those whose workplace behaviour is deemed to be unacceptable.

As we write this paragraph, Christopher has flashbacks to his experience of a 'sheltered workshop' very close to where we work together this day. Seventeen years old, he packaged refresher towels and plastic knives and forks in heat-sealed bags for fast-food chain Kentucky Fried Chicken. In the breaks, the workers, all people with disabilities, gathered at particular tables in the workshop, while management (those without disabilities) ate at separate tables. The two groups never mixed. Workers received virtually nothing for their labour, and management received award wages. While reforms in sheltered employment have occurred in the last few decades,

many people with disabilities still know the realities of not just sheltered workshops but 'diversional centres' where people with 'special' needs are sent for secluded recreation options to divert them from the oppressive reality of a society that finds those who drool, whose bodies and minds are marked as too different, and indeed who inspire fear and trepidation in social circles, as impediments to sociability. We feel so much better as a society when we 'care' for those we know to be imperfect, subhuman and genetically flawed, in designated facilities and support programs set aside from 'normal' society. The common rationale for such a situation and for such policies is that 'we are doing it for them'; that we tend to their needs rather than our own insecurities; we are acting selflessly and with beneficence and benevolence – the very antithesis of being selfish.

Encountering disability

In this book, we seek to challenge the peculiar and powerful exclusion of people with disability in Australian society. To do so, we wish to provide an introduction to new ways of thinking about disability. We hope to provoke discussion, reflection, questioning, argument, and, ultimately, add to a fragile, new conversation emerging regarding disability in Australian society. This collective activity, naming, renaming and imagining is what we aim to contribute to with this book, which we regard as one way that a reader can, yet again or for the first time, encounter disability in society. Our interest in disability is personal, as much as it is political and intellectual.

Christopher is a person who lives with disability and has long been active in the Australian disability rights movement and disability studies. He also teaches medical ethics at the University of Tasmania. This book is an expression of many of the forms of exclusion, oppression and apartheid that he has known and continues to know in the everyday. He failed at school – and then found that to be an expression of a disabling educational system. He knows full well the limited employment and social options which really become 'equal disappointment opportunity'.¹⁴ He longs to move beyond the daily devastating experience of being 'brave', 'special needs', 'failed patient', and of course the objectified 'wheelchair in row 4E', to

become 'Dr Newell', the esteemed commentator, academic and customer.

Gerard does not identify as a person with disability, but has been personally interested in the area since working with people in the disability movement in the early 1990s. His relationships with people with disabilities, his activist and policy work, and his research and writing have made him fundamentally question his own cherished ideas about his identity, his body and his own investments in what is 'normal'. Encountering disability has been an adventure in exploring new ways of understanding himself, his relationships to others, and his own ambivalent placement in disabling institutions and policies. Gerard wishes to continue a conversation about disability: something he feels is at the heart of a general project of justice, human rights and democracy.

✱ To start with, what do we mean by disability? In due course, we will see how society has defined and even regulated disability via laws and institutions. Yet, at a more basic level, we all know what disability is, do we not? When we think of people with disabilities we tend to focus on stereotypes of physical disability; such as someone 'confined' to a static wheelchair, someone with crutches or a cane, someone who is blind, or who cannot hear or speak. We might think of people with intellectual disability or acquired brain injuries, and then we often involuntarily murmur a sub-text such as 'thank God, I don't have a disability'. Disability is something that we would rather not have, do anything to avoid, and try to prevent:

The average, well-meaning 'normal' observer feels sorry for that disabled person, feels awkward about relating to the person, believes that the government or charity should provide special services, and gives thanks for not being disabled (as in 'I cried that I had no shoes until I met a man who had no feet').¹⁵

Disability we know as an objective fact – you are either disabled or not disabled – a fixed life sentence, a catastrophe, or even tragedy, which in similar ways to an ancient Greek tragedy remorselessly works its way through our lives, influencing their every aspect. Yet disability is a tragedy that does not culminate in any grand conclusion. It is just an ongoing tragedy, without a denouement. It makes

sense, then, that we commonly refer to the death of a person with multiple disabilities as a 'merciful passing' or 'blessing'.

The tragedy we know of as disability is defined as medical fact: from the diagnosis of disability at the pre-natal stage, identification of disability in children, early adult acquisition of disability through accidents, right through to the onset of a variety of disabilities later in the life cycle. We 'know' if a person has disability because this is commonly felt to be their defining attribute. Very often we refer to people as 'quadriplegics', 'diabetics', 'deaf', 'mute', a 'dwarf', or as a 'Down's syndrome'. Disability is located in the person who is its bearer. He or she is subject to a life sentence of suffering pain, discomfort and loss of functioning.

As the word 'disability' suggests, a person with disability is the opposite of someone with 'ability'. Historically, a person with a disability has been seen as 'incapacitated', not having capacities. The word 'handicap' came to be used in the nineteenth and twentieth centuries to describe 'disability'. Also, to be a person with disability was to be regarded as 'abnormal'. To be a person with disability is to deviate from the 'normal': to be a deviant who needs to be helped and managed.

Society has developed ways of dealing with the deviance and incapacity of disability. Strong social institutions, some of them special, some of them routine, help us individually and collectively to deal with disability. We have charities (the Royal Blind or Deaf Societies, the Spastic Society, the Multiple Sclerosis Society) and events ('button' days, beauty contests, telethons), which raise funds for people with disabilities as the passive recipients of care and welfare. These charities have indeed provided care and support for people with disabilities, because governments or business organisations did not do so. During the twentieth century, governments took on greater responsibilities for the welfare of its citizens, especially after World War II. However, in Australia, the aftermath of World War I, and the existence of a significant group of impoverished blind war veterans, whose situation was deeply disturbing to the Australian population, saw the creation of the Blind Pension – a precursor to the pensions we take for granted today. With the demise of the welfare state in Australia, especially after the 1975 defeat of the Whitlam Labor government, the last

nearly three decades have seen significant developments in how we understand and manage disability.

Here we are reminded of the way in which our lives have been shaped by this recent history. Christopher recalls that in 1982 he was granted an Invalid Pension by the Australian government's Department of Social Security. Such a payment was based on a person being totally unfit for work – an 'invalid'. In Christopher's case, he was in hospital more than he was at home, and was not expected to live. Having been able to gain some tertiary education via distance education (often from a hospital bed), in the late 1980s Christopher was able to take advantage of a rethink of welfare for people with disabilities, which saw the introduction of the Disability Support Pension. Here the emphasis was not so much on people qualifying for government support only if they were deemed absolute invalids, rather there was a recognition of people with disabilities being able to undertake some employment, often casual, even if it was not full-time. Christopher still recalls his incredulous delight when he was offered a part-time position tutoring external students. It was a significant move from 'passive' welfare recipient to having some valued role in life.

In the 1990s perhaps the most striking move in social institutions of disability has been the increasingly corporate approach. Organisations have moved to excise terminology such as 'crippled' or 'handicapped' from their charities' names, despite the fact that many would benefit from the enduring attraction potential donors may have for 'helping' those who are manifestly deserving. Words such as 'crippled' and 'spastic' are extremely evocative, as shown by their continued use by teenagers, and others (including politicians, as we discuss in chapter 6), as expressions of contempt and derision.

For all of the developments with regard to disability that may be seen as 'progress', and our sense that we are an 'enlightened society', something is fundamentally wrong with dominant ways of perceiving disability in which disability remains as the hallmark of otherness. Language may be changing to excise overt discrimination, but are our unstated norms and attitudes?

(We are here mindful that in making the point about the importance of language, we should explain our own. In the United Kingdom

the disability rights movement has largely adopted the language 'disabled people' for political reasons as a way of emphasising how people with impairments are made disabled by society. Yet in Australia and the United States we have adopted a different approach and largely use the terminology of 'people with disabilities'. There is also the variant 'people with a disability' beloved of the bureaucracy. We have largely taken the language of the Australian disability rights movement in using the terminology either 'people with disabilities' or in a variation 'people with disability'. While not largely used, we like the latter phrasing because it does tend to stress disability as not the personal attribute of a person.)¹⁶

When we listen to the narratives of so many people with disability, we can discover a radically different understanding of the world. This understanding is one which suggests that certainly we have impairments located within body and mind – you cannot take those away, despite the perpetual promises of medical science and the cure just around the corner. Yet when we move to understand disability as more than objective medical fact, we can understand the many ways in which disability is created and perpetuated by society and its structures.

A person with a wheelchair is perhaps the universal symbol of disability. But what does it mean? A person with spinal cord injury acquired in a car accident will commonly go through a significant period of grief and loss. All the things that are so significant in life are changed – employment, relationships, going to the pub, driving a car, doing so many things spontaneously. The way people with acquired disability are viewed by many people around them may also change utterly and be a cause for great distress. Now often people look at them differently, with a pitying or annoyed look, may talk to them differently, in a patronising or sympathetic way, and instead of talking to them directly, often will communicate with them via their companions and talk about them in the third person.

But how much do people really change? Yes, they are now identified as disabled, and may themselves choose to identify as such. But is their experience of social life so very different? The question emerges here as to whether the tragedy lies in the paraplegic body or in the society and culture in which the person lives. A person

may no longer be able to walk either unassisted or for distances, using a wheelchair for mobility and travel, but why should the fact that he or she uses a wheelchair stop them from enjoying going to the cinema or to a café or pub, having friends and being in an intimate relationship, earning a living, having children, or travelling on holiday? Why should the fact that they are regarded as having a disability preclude them from being treated by society as an equal, as a citizen, as 'normal'?

Consider the story of Alison Davis, a disability activist born with disability:

I was born with severe spina bifida, and am confined to a wheelchair as a result. Despite my disability and the gloomy predictions made by doctors at my birth, I am now leading a very full, happy and satisfying life by any standards. I am most definitely glad to be alive.¹⁷

Certainly, it may be argued that Alison Davis' case is in many ways exceptional. She was granted access to the necessary resources and life situations, including the necessary support for her family, which allowed her to lead what many would view as a successful life.

If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would not be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida.¹⁸

The challenge posed by Davis' story is one we take up in this book. To understand how we encounter disability in society, we need to redirect our gaze away from the person with disability to scrutinise society itself as the site where disability is located and reproduced. In levying such a critical gaze at the places where disability is located and reproduced, we also come face to face with an apartheid of disability.

The social nature of disability †

A parable about how society constructs disability, and what this means, is told by Vic Finkelstein, a British academic with disability.

Finkelstein posits an imaginary society where a thousand or so people, all of whom are wheelchair users, settle in a village and organise a social system to suit themselves, with its own design and building codes. At some stage a few able-bodied people come to live in the village, but they do not fit in. They are constantly knocking their heads on door lintels, and require constant medical intervention and control. Special aids have to be designed for the so-called able-bodied, now the disabled members of the village. They are given free helmets to protect their heads, and they have difficulty obtaining work because of their deviation from the norm: as a result, they become objects of charity. 'In such an imaginary society,' Finkelstein writes, 'it would be possible for physically impaired people to be the able-bodied!'¹⁹

The implication of Finkelstein's thought-experiment is that we cannot understand disability without understanding the way disability is socially shaped. A new understanding of the world emerges from such a radical perspective, turning disability on its head. This 'social' approach challenges the dominant 'medical' model of disability as biological certainty, individual pathology, deficit and loss to be diagnosed and managed by modern medicine.

For example, British theorists of the 'social model' of disability propose a distinction between 'impairment' and 'disability'. Impairment is the bodily dimension, whereas disability is what society makes of someone's impairment. Disability is not 'natural' or 'given'; rather, it is the social processing, relations and meanings attaching to the impaired body and mind. Disability is a social, cultural and historically specific phenomenon. The architecture of our buildings, villages and cities and how they are arranged in space is an important determinant of disability.²⁰ Disability is no more an unarguable biological 'fact' than is gender or race; in fact, disability interacts intimately with the categories gender, race, ethnicity, class and sexuality, being integrally involved in the production of these social 'facts' and power structures.

Similarly, in Australia and other white settler societies, indigenous people were believed to be primitive and backward. Strenuous attempts were made, especially in the nineteenth century, to distinguish between 'white' and 'black', and fractions in between, in order to ensure those deemed 'black' kept to their allotted roles, or were

bred out. Indigenous people, as is now being widely acknowledged, were regarded not only as biologically inferior but also as less than human. As subhuman, it was then the more easy to regard the lands they occupied as terra nullius. In the wake of feminism, indigenous rights, post-colonialism, and other movements, it is more difficult to simplistically hold, if to hold at all, that women or indigenous people are biologically inferior. Rather, the critical gaze of many scholars has turned from studying women or indigenes as the 'exotic' other, to studying, for instance, the unmarked gender or race of the dominant position. We now understand that it is as important to study the construction of masculinities as it is to study femininities, or that we need to analyse whiteness as much as blackness and indigeness; and that it is imperative to understand the forms disability takes when combined with other categories. Here we encounter the rich problem of category politics, where we are not allowed to be, at one and the same time, a woman and disabled, Aboriginal and part of the disability movement.²¹

To think of disability as social has profound implications. Take for instance the still powerfully prevalent medical classification of disability. For example, we customarily divide disability into kinds; such as T4 or T5, referring to the location of fracture in the spine of a person. From that flows not just a classification of functioning but the classification of the people themselves. Declaring someone to be a T4 (the fourth thoracic vertebrae) will refer to a location of injury on the spine with implications for understanding functioning, but it need not be anything more.

In the urge to classify that which characterises the disablist world view, we can discern the will to mastery that, under the guise of 'knowing', seeks to fix and regulate not just the unruly bodies of others but our own. We wonder, then, whether this is why people with disabilities often evoke discomfort, unease, fear or pathos among those who do not consider themselves disabled (but who are sometimes termed the 'temporarily able-bodied'). We all experience disquiet, anxiety and, sometimes, fear about the bodies in which we live our being. Our bodies are frail. We age. We fall ill. We lack energy. We feel our bodies fail us. We are mortal; though we may wish to live for ever.

Understanding disability as social opens up new perspectives on

science. Genetics and various forms of biotechnology are of great contemporary interest. A widely shared scientific and popular assumption is that the nature of a person is to be found in their genes. What you are is predetermined, hard-wired in your genes. A constituent part of such a make-up is the very diseases that are identified by genetic science. Take, for example, the case of Down's syndrome or conditions such as Fragile X: chromosomal conditions which impact upon human intelligence. An important question is whether the lives of people with these conditions are predetermined as a form of tragedy, or whether we visit the tragedy upon those who deviate from the norms of intelligence.

The impairments associated with Down's syndrome are transformed into the social construction of that condition as disability. One aspect of the fear that pregnant women, their partners, family and friends have regarding the spectre of a baby with Down's syndrome may actually be a well-founded concern with the lack of support available for rearing and caring for such a child and ensuring the child enjoys full access and participation to all areas of cultural, economic and social life. Medicine is able to calibrate the possibility of a particular woman giving birth to a child with Down's syndrome, and what the likely impairments of such a child may be. However, this only takes us so far in understanding what the life of someone with Down's syndrome might be, and what our life experiences might be as someone living, working and being friends with or lovers of them. Many of the difficulties someone living with Down's syndrome experiences spring not principally from that person's impairment and its health consequences. Rather, the problems are caused by prejudice, discrimination, poor design of technology, inaccessible workplaces, and lack of appropriate education and training. Or by lack of funding and resourcing for disability support and advocacy organisations, carers, and other social support mechanisms that ensure that society as a whole supports its members; rather than the lion's share of the burden being placed on the shoulders of the family, and so being experienced as overwhelming.

One of our friends, John, has the disease-label, Down's syndrome. Many predictions of his quality of life were made before, and after, his life commenced. John does not know all of the things that are said about him. He lives in supported accommodation, and spends more

time enjoying himself than some of our other friends without disability. According to some people, John's life is not worth living, but this is not his view. Modern genetic science has developed ways of screening for conditions such as Down's syndrome; yet, when we consider the lives of people such as John we recognise that his life journey is far more than a preordained tragedy scripted by his medically diagnosed genes. Like many people with disability, and all of us, John can have a high quality of life or a low quality of life. To a significant degree, this depends on social structures which enable or disable.

None of us wishes to have a child with disability. One of the profoundly important things we all wish in having children is that they are 'healthy', although we struggle with what this really means whenever we go beyond the taken-for-granted meaning. The incidence of disability in children tends to prompt us to explore such concepts as health, normality and what a good life is. As parents we all hope our children can reach their full potential. Yet all of us have limitations. Without wishing to sound overly pious, all of us can even grow through the difficulties of life. Many of us will not become brain surgeons, millionaires, firefighters, police, pop stars, or be leaders of our country. To some extent our skills may well be associated with our genetic make-up. There are other reasons underlying our life chances and achievements: the interacting factors of class, income, social status, ethnic and cultural group membership, gender, education, and even making sure that we are born and live within the right postcode. Many of the most profound barriers that we will encounter in life are social. This is particularly the case for those identified as having a disability, because that label and definition is so overwhelming, so indicative of otherness that it is difficult even to conceive of people with disabilities as successful in so many meanings of that word.

As a society, we are very good at identifying the cost of disability. It has been estimated in some studies that it will cost the community some \$2 million in care, over the life of a person with Down's syndrome. Yet, we wonder if the costing has been done as to how much prime ministers or chief executive officers of large companies cost their community, especially with the ever-expanding perks of such offices. Of course, there are fundamental differences, but primarily this is because we think of people with disability in terms of being passive consumers of care, and prime ministers or captains of indus-

try as being active contributors to society.

Our pessimistic and inaccurate preconceptions of the cost of disability are not helped by the fact that Australia is a country in which public debate and policy formulation is dominated by narrow neoclassical economic frameworks ('economic rationalism', as it is popularly termed). For example, prominent medical ethicist Julian Savulescu notes that it is 'probably unlawful to place lower priority on children with Down's syndrome and other disabilities, who need heart transplants'.²² He proceeds to ask, 'But is it unethical?'. Savulescu's answer is that it is indeed justifiable to place a lower priority on children with Down's syndrome in a climate of finite resources. A similar argument is developed by Peter Singer and Helga Kuhse.²³ Such an economic discourse, and its ethical correlates, lacks the values, concepts and methods to comprehend – and allow – the full benefits as well as costs of disability, and the complex issues posed in resource allocation, consumption and production. Indeed, within Western societies more generally, and specialised bioethical debates, we see the rise of utilitarian calculus premised upon the tragedy of disability. The concept of disability deployed in such economics and ethics derives from a coupling of the medical model's account of disability as deficit, and the charitable discourse that sees people with disabilities as passive recipients of society's munificence, while being exorbitant consumers of its scarce resources.

Disability and culture

In this book, we explore the social nature of disability, and its relations of power. To understand this phenomenon of disability in society, and why social practices and institutions are very slow to change, we need to turn to culture. Culture is intimately related to society, and is something difficult to define. However, we wish to propose that culture in Australia depends in important ways on disability; and that the situation of people with disabilities is very a culturally bound and shaped dilemma.

A helpful example here is that of deafness and hearing disability. From the dominant biomedical perspective, someone who is deaf suffers from loss of hearing. The efforts of the medical fraternity and of society more generally should be placed on finding ways to restore,

prevent, or ameliorate the deleterious effects of hearing loss. Technical ingenuity has seen sophisticated hearing aids developed which can amplify and improve residual hearing. Social practices have also been developed to serve as a proxy to provide linguistic information hearing affords. Lip-reading, for instance, is a skill that people can learn in order to decipher what people are saying. However, for approximately 25 000 Australians who call themselves capital 'd' Deaf, to be Deaf is to belong to a cultural and linguistic minority who communicate in Australian Sign Language (AUSLAN), like Australians who speak Greek or Vietnamese. The significant distinction between the larger group of nearly half a million Australians with hearing loss, of course, is that most members of the Deaf community are either born deaf or pre-linguistically deafened.

Nothing will take away the sense of loss associated with a hearing person losing their hearing. But why is this? To a significant extent, it is because we are not able to undertake the functions and to do the things that we take for granted as hearing people: to listen to others speak, to hear sounds, noise and music. We need to recognise that there are other ways of communicating and interacting socially. When we see Deaf or hearing people communicating in sign language, we tend to frame such a scene through our own cultural assumptions and meanings. Indeed the way in which we write this analysis is framed in accordance with hearing norms. In the very recent past, the orthodoxy was that sign language in Deaf people, especially school children, should be discouraged if not banned. Rather, Deaf children should be taught to lip-read and to use whatever residual hearing they may have. This philosophy was called 'oralism', and it was officially adopted internationally over a century ago at the 1880 Milan conference.²⁴ In the 1980s and 1990s in Australian schools, there were frequent instances of Deaf children being punished for using AUSLAN.

Yet, as hearing people, in our knowledge of our cultural superiority, we rarely acknowledge that AUSLAN can actually be expressive in ways that spoken English is not – especially as it is a language that operates in a visual modality. There is no reason why a hearing impairment cannot become understood by a society in a culturally affirmative way. For instance, we are reminded of the historical example of Martha's Vineyard, an isolated island in the United States,

where the incidence of genetic deafness was associated with the dominant language used on the island by deaf and hearing people being sign language. AUSLAN only quite recently became an official community language in Australia. We wager that more resources still are put into preventing and curing deafness than properly funding the training and operation of AUSLAN interpreters and language teaching in schools. The cochlear ear implant, for instance, is commonly celebrated as the apex of Australian scientific, engineering and business acumen, and seen as a device that should automatically be implanted to improve the hearing of appropriate recipients with hearing disabilities. Some proponents of the cochlear implant continue to disregard the implications of inappropriate application of such technology for Deaf culture. The highly contentious issue is whether or not children should be implanted, as this has significant implications for whether they are raised as children with a hearing disability or as Deaf people whose first language is AUSLAN. There are some similarities here with debates over the cultural implications of technologies such as television or the internet, for minority language and cultural groupings.

Much of the cultural life of Australians now takes place through media, whether television, radio, magazines and newspapers, audio-tapes and Braille material, or new media such as computer games, the internet, and mobile phones. In a 1998 article columnist Phillip Adams celebrated the life of Elizabeth Hastings, a disability activist who became the first Disability Discrimination Commissioner. Adams talks of a salutatory lesson he learned when devising the Australian campaign for the International Year of Disabled Persons (IYDP) in 1981. He was all set to proceed with a campaign conforming to dominant stereotypes – one which celebrated individuals overcoming the tragedy of disability in profound personal triumph. The plans were well progressed when finally he spoke to a few people with disability, including Elizabeth Hastings, who turned his thinking completely around. As a result he came up with the award winning IYDP campaign 'Break Down the Barriers'.²⁵ Adams' story is a rare one, unfortunately. People with disabilities are generally represented in stereotypical and disabling ways in Australian mainstream media, even 'new media' technologies and forms. The construct of disability represented in media culture is generally a limited one, They do not

participate on equal terms as workers in media industries, and, unfortunately with few exceptions, mainstream journalists, editors, producers, film and video makers, scriptwriters, computer games designers, multimedia content producers, and those devising cultural material for online and mobile phones do not produce the diverse representations of people with disabilities across various genres that are expected of other groups.

Media plays a central role in culturally embedding the profound sense of otherness that many people with disabilities experience. Indeed the media tends to show us a very limited construct of disability, often masculinised too – the figure of Elizabeth Hastings was an exception to this rule perhaps. Organisations like Women With Disabilities Australia came into being as a consequence of contending with the gender politics of media and many other spheres of life, but their critiques are rarely carried even on issues which directly involve them and the bodies and lives of other women.

To understand disability and power, we need to decipher our ways of being and becoming in culture. For this reason in this book we do a great deal of cultural and media analysis of disability, drawing on approaches from cultural and media studies – disciplines that as yet have not engaged in an indepth and sustained way with critical disability studies.

Disability by rights

For all that we find social understanding of disability to be helpful in explaining many dimensions of the everyday experience and reality of people with disability, such an account does not adequately address some of the inescapable dimensions of disability found in a medical account. For all that we may explain disability sociologically, the daily experience of chronic pain, devastating depression, and even a variety of disabling conditions which require medical treatment in order for us to stay alive, mean that we cannot arbitrarily dismiss the experience of people with chronic conditions that do not fit neatly into an either/or account implied by contrasting oppositions between 'impairment' and 'disability'. Yet such experiences are themselves socially mediated and culturally inscribed.

We need also to be wary of the problem associated with throwing

out a medical account when its replacement with a more bureaucratic approach to managing the problem of disability has in itself been just as controlling. We are heartened, for instance, that the social model can be fluently explicated by the Productivity Commission in its Issues Paper for its 2003 inquiry into the *Disability Discrimination Act*. Yet it also gives us pause, and makes us wonder whether this version of the social model is too neat a fit with contemporary governance of disability.

For us, these problems suggest the need to find a path beyond both the medical and social models, taking the cultural dimension of disability seriously and integrating this within a human rights approach. Here we are mindful of the problems of 'rights talk'. For instance, the rise of capitalism and Western liberal democracy since the eighteenth century has been accompanied by a discourse of rights which is increasingly individualist in focus.

In the late twentieth century, such rampant individualism has underpinned capitalism (not least in the Thatcherite emphasis on the rights of the individual to make money, or the conservative Australian obsession with rights of workers to be placed on individual contracts) through to accounts of rights where ethical thinking revolves around rights in relationship with others in community. Rights talk in this broader sense in Australia has tended to be confined to narrowly conceived 'civil' and 'political' rights – the freedom of expression and assembly, and freedom of individuals to enter into contracts. The sole focus on civil and political rights has been critiqued by those, especially in developing countries, who argue for the importance, alongside this, of economic rights. Others, such as Karl Marx himself, have argued that rights are a bourgeois concept that does not adequately capture the inequality and oppression under systems of economic and political oppression such as capitalism, patriarchy, homophobia, racism or colonialism.

Rights were consolidated in the international legal and diplomatic framework with the 1948 Universal Declaration of Human Rights and the key covenants that have arisen to complement this. Though more observed in the breach perhaps, the pursuit of human rights is still crucially and strategically important in the early twenty-first century, as a framework for dealing with issues of oppression and freedom in a world where older political categories are being reworked.²⁶ We see human rights in a broad sense, nourished in and by community. They

have civil, political and economic dimensions, as well as encompassing dimensions of human freedom and human potentiality revealed in contemporary struggles by feminist, indigenous, sexual, religious, anti-colonial and disability movements.

Legislating disability

Throughout the Western world, a significant response by legislators to some of the experience of otherness felt by a variety of marginalised population groupings has been found in anti-discrimination legislation and an invocation of rights. In more recent years there has been a trend towards specific legislation tackling the incidence of disability. In the United States there was the *Americans with Disabilities Act* 1989; in Australia there has been the *Disability Discrimination Act* 1992 (Cth), as well as state legislation in the form of equal opportunity laws commonly outlawing discrimination on the ground of disability; and in the United Kingdom, the *Disability Discrimination Act* in 1995.

Passed by both Houses of Parliament with bipartisan support on 15 October 1992, the Australian legislation provides a good case study in how such legislation actually can be significantly disabling, in addition to the clear ways in which it can enable and outlaw particular forms of discrimination. In the peroration to his second reading speech, then Minister for Health, Housing and Community Services, the Hon. Brian Howe declared:

Our vision is a fairer Australia where people with disabilities are regarded as equals, with the same rights as all other citizens, with recourse to systems that redress any infringements of their rights; where people with disabilities can participate in the life of the community in which they live, to the degree that they wish; where people with disabilities can gain and hold meaningful employment that provides wages and career opportunities that reflect performance; where control by people with disabilities over their own bodies, lives and future is assumed and ensured; where difference is accepted, and where public instrumentalities, communities and individuals act to ensure that society accommodates such difference. Only then will we be able to say that justice has been achieved.²⁷

In Australia the definition of disability used in the *Disability*

Discrimination Act is quite extensive, covering: physical disabilities including physical disfigurement; intellectual disabilities; psychiatric disabilities; sensory disabilities; neurological disabilities; learning disabilities; presence in the body of a disease causing organism; past, future and imputed associates. This means that many people are covered by the *Disability Discrimination Act*, and that it is a law that applies to many areas of our daily lives.²⁸ However, it is most significant that key aspects of the lives of Australians with disabilities are excluded. These areas include migration, social security and insurance (where there are actuarial tables in existence to support discrimination).

More than ten years since the *Disability Discrimination Act* came into effect, there is evidence of its positive role, not least through its complaints-based process – as the Human Rights and Equal Opportunity Commission has noted in its review of achievements under the legislation.²⁹ Elsewhere, in the 2001–2002 HREOC *Annual Report*, Human Rights Commissioner and Acting Disability Discrimination Commissioner Dr Sev Ozdowski observes that:

There have been some substantial achievements [since the commencement of the *DDA*]. In particular, achievements include widespread progress in accessibility of public transport, and increased accessibility of communications and information to people with sensory disabilities. However, there are also many areas where progress has been slower than might have been hoped.³⁰

Ozdowski points to the slow progress of standards setting, the lack of effectiveness of the legislation with respect to employment, and acknowledges that:

... we have been able to achieve less for some sections of the disability community so far than for others using the *Disability Discrimination Act*. In particular, people with intellectual or psychiatric disabilities have not had the same clear benefits as people with physical or sensory disabilities.³¹

We would also point to the steady undermining of HREOC and its power by the Coalition government since it took office. In the disability area, the government has refused to appoint a permanent commissioner since inaugural Disability Discrimination Commissioner

Elizabeth Hastings retired in 1997. The next three commissioners, Susan Halliday, Chris Sidoti and now Dr Sez Ozdowski, have all served as 'Acting' Disability Discrimination Commissioner, without a permanent appointment to the position. While each of these three commissioners has provided important leadership, none of them has been a member of the Australian disability community. More recently, the government has made an attempt to curtail the powers of HREOC to initiate action on instances of discrimination – a blatant attempt to diminish the independence of the Commission as the agency that would challenge discrimination.

There is a growing critical literature with regard to significant problems with people with disabilities actually being able to afford to gain access to using such legislation, especially since there has been a requirement for cases to be heard in the Federal Court with significant risks (not to mention the issue of constitutional problems with enforcement).³² An action under the *Disability Discrimination Act* is an action where you could potentially lose your house in the Federal Court. This is particularly the case given that so often in legal matters notions of 'reasonable' revolve around non-disabled accounts of reasonable and unreasonable.³³ It is not surprising perhaps, then, that HREOC's tenth anniversary publication seeks to recognise the often difficult nature of taking a complaint to the Commission³⁴ and to affirm that this is worthwhile.

One notable exception where justice was gained, and the concept of 'reasonableness' appropriately critiqued and nuanced, is the landmark *Scott & DPI(A) v Telstra*. In this case then President of the Human Rights and Equal Opportunity Commission, Sir Ronald Wilson, drew explicitly on the concepts and rhetoric of human rights in finding for Mr Scott, a Deaf man found to be discriminated against by Telstra in its provision of telecommunication services.³⁵ However, we would suggest that even in such a case there are significant ways in which such legislation creates disability.³⁶ In particular, the Deaf community (predominantly pre-lingually deaf, and united in the use of Australian sign language as their first language) have had to identify as having a disability in order to utilise this legislation. Prior to this, the community had staunchly identified themselves in terms of being a linguistic minority rather than a disability category. Since the introduction of the *DDA* they have been required to conform to hearing-world norms in

identifying as having a disability in order to gain access to the benefits of such legislation.

It is also notable that even the standards used under such legislation can help to entrench accounts of otherness. An example is the much-vaunted Transport Standard recently introduced, which is supposed to make Australia's public transport accessible over a period of twenty years. Yet, such standards tend to reinforce dominant accounts of disability: stereotypes of people with disability as people with obvious physical disabilities, such as users of wheelchairs. Narrowly conceived standards do not address the needs of people with a wide range of other impairments, such as chemical sensitivity or even intellectual disability. Inadequate standards are of great concern given that their approval and adoption then provides a significant defence for bus operators against any claim of discrimination by people with disability. It is also noteworthy that there has been a significant backlash against the rights of people with disability, conferred by such legislation. In America, well-known disability activist Mary Johnson documents the way in which two well-known actors, Clint Eastwood and Christopher Reeve, have participated in the clawing back of provisions of the *Americans with Disabilities Act*.³⁷

We would suggest that it is because of the historical and current constructions of disability that it remains on the human rights movement agenda. That situation is not just with regard to Australia but within the international community. Disabled Peoples' International, a movement for and of people with disabilities came about precisely because people with disabilities did not have an adequate voice in the global organisation Rehabilitation International, dominated by non-disabled providers. In Australia that situation was reflected in the domination of the Australian disability scene in the 1970s and 80s by ACROD Ltd (formerly the Australian Council for the Rehabilitation of the Disabled).

Even today within the United Nations system, many different social groups are explicitly dealt with and accorded appropriate respect and weight. Yet the organisation Disabled Peoples' International and representative organisations of people with disabilities do not have the observer status of organisations such as Rehabilitation International, dominated as it is by non-disabled inter-

ests.³⁸ The existing six core human rights treaties of the UN were 'drafted without regard to disability', according to the UN Special Rapporteur on Disability, Bengt Lindqvist.³⁹ It is a positive step indeed that as this book goes to press a third attempt is being made to bring about an International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. It is sad, however, that the Australian government has been slow to recognise the importance of such a convention, and that it did not invite the participation of Australian disability non-government organisations (NGOs) to the first international Ad Hoc Committee meetings in New York in July and August 2002.⁴⁰ It is pleasing to note the participation of NGOs in later meetings. Of course, the real test of such a convention will be whether or not citizens with disability around the world experience liberation and increased opportunity in daily life.

Disability in Australia

The aim of equal opportunity and anti-discrimination legislation is laudable. In the area of discrimination, such laws have brought about some important changes and real improvements in the lives of people with disabilities. Yet fundamental transformations to society are only slowly occurring, with great resistance, whether with outright opposition or silent inertia. It is in this scene of the terribly slow coming to full participation in society of people with disabilities that this book is set.

We wish to provide an overview of disability in Australia in the present day, offering a perspective of disability in six important areas of society: health and welfare, sport, biotechnology and genetics, deinstitutionalisation, politics, and migration.

Part 1, 'Bodies apart: systems of othering', looks at three fundamental areas of importance, and sketches the way people with disabilities are excluded and set apart in these. We open in chapter 2, 'Health, welfare and disability', with a discussion of how people with disabilities look after their health and make ends meet. The medical model of disability has particular power in our health system, controlling people's very bodies, but finds its way, too, into questions of welfare and who society chooses to support and how it does so. In chapter 3, 'Handicapping sport', we reflect on that quintessentially Australian pursuit – sport. We look at the triumphal 2000 Sydney Olympics in

which people with disabilities were firmly positioned in the margins, with their own 'special' Paralympic games. From the celebration of national achievement and values in elite Olympic sport, we move, in chapter 4, 'Biotechnology and designer disability', to consider how the needs, interests and participation of people with disabilities are very often absent from the shaping of technology, despite the fact that it may be used to control rather than liberate them. Technology has become an important part of modern medicine, and nowhere is this more so than in the glamorous field of biotechnology where real possibilities for creating and modifying human beings are emerging. It is commonly assumed that people with disabilities are the natural beneficiaries of such technology.

In part 2, 'No place like home: belonging and citizenship', we turn our attention to three major areas of society in which people with disabilities should feel at home, in the deepest sense – but presently do not. In chapter 5, 'Reinstitutionalising disability', we consider the way that people with disabilities have been excluded from society through being placed in institutions. The movement of deinstitutionalisation from the 1970s promised to reintegrate people with disabilities into society, but its many successes have been outweighed by lack of resources, oppressive practices, and the continuation of institution-alisation in different forms. Australian political institutions are the subject of chapter 6, 'Political life and a disabled republic?'. How can Australian society make the needed radical transformation in the direction of justice for all, if people with disabilities remain absent from our government, our political parties and from our very constitution? People with disabilities have even been almost completely absent from our ideas of a republic, and so we call here for rethinking of the bases of Australian political life. The Australian polity is comprised and governed, so we believe, by citizens acting together. In chapter 7, 'Refugees and the flight from human rights', we reflect upon one of the greatest shortcomings of Australian society as a whole – the exclusion and incarceration we mete out to those who seek refuge in our country, and what this means for our cherished notions of citizenship. While the refugee debate has been of central national importance since the 2000 federal election, the disability dimension of asylum seeker experience and policy has not received much attention. Here, we look at the treatment of migrants and

refugees with disability, and the creation of disability in immigration detention.

In our conclusion, chapter 8, 'Conclusion: Reclaiming a civil society', we suggest that not only are people with disability some of the most disadvantaged of Australian citizens but, in a whole range of ethical, political, social, economic and spiritual debates, they provide an important litmus test as to whether or not we have a vision and a plan for a truly just society. Rather than seeing disability as inherently uncivil, uncivilising and deeply distressing, we need to encounter disability as an inevitable, normal and indeed positive part of the diversity of Australian society, to be celebrated. In every aspect of Australian society, the situation of people with disabilities provides us with a significant challenge to understand our lived values and even to dare to ask: how can we embrace people with disabilities as part of the civil society and society in general? We contend that the real political question should not be whether we should embrace people with disability within a vision of a just society but, rather, if in our social institutions and day-to-day ethics we dare to do so.

Throughout this book, we build upon the important work done by many policymakers, people with disabilities and their organisations, charities and non-government organisations, and other academics. There have been a number of important edited books on different aspects of disability: notably, Mike Clear's *Promises, Promises: Disability and Terms of Inclusion*, with its ensemble of creative and sophisticated evaluations of disability in New South Wales as well as national policy and practice;⁴¹ Marge Hauritz, Charles Sampford and Sophie Blencowe's *Justice for People with Disabilities: Legal and Institutional Issues*;⁴² and Errol Cocks's *Under Blue Skies: The Social Construction of Intellectual Disability in Western Australia*.⁴³ In addition important legal analysis has been offered by our legal colleagues Melinda Jones and Lee Ann Basser (as she is now known) in their works *Explorations on Law and Disability in Australia* and *Disability, Divers-ability and Legal Change*.⁴⁴ We hope to contribute new analysis and a broad, national perspective on disability, a counterpart to available accounts of disability in other countries, such as Marta Russell's *Beyond Ramps: Disability at the End of the Social Contract*,⁴⁵ in the United States, or Jane Campbell and Mike Oliver's *Disability Politics: Understanding Our Past, Changing Our Future*.⁴⁶

Our account is by no means an exhaustive audit but we hope to accurately depict disability in Australian society and identify the prime reasons why people with disability continue to live as a people apart. To properly understand our topic, we analyse a diverse range of texts, institutions, social practices and cultural forms. In particular, we firmly believe in the need to trace the connections between the different levels of the economic, social, political, cultural, symbolic, ethical and spiritual. To explain why justice for people with disabilities has still not been achieved, we equally consider the social nature of disabilities and the human rights of people with disability, as well as matters of culture and ethics.

Crucially also, we wish to make new ways of thinking about disability accessible to wider audiences for whom disability may be regarded as a 'specialist' topic or minority concern. We wish to address readers who already have an interest in disability – as people who identify with disability; as family, partners, friends or carers of people with disability; as people delivering services to, making policy for or working with people with disability; as people with a concern for human rights and fighting oppression who wish to know more about how disability relates to wider questions of justice; or people who are simply curious about what disability is. You can see that we have already made a start with this in our choice of cover illustration for this book – a photo of an Australian with disability now living in England, Caroline Bowditch. In beautifully evoking disability as something that transcends evil and negative stereotypes of males in wheelchairs, this image indicates where we want to be. We claim the sexy nature of people with disability and the ability to be playfully devilish as opposed to being devil-ridden.

As well as offering an anatomy of disability, we aim to provide a critical introduction to disability for general readers and for students studying disability. Our approach to disability, and our central focus on power, comes broadly from the humanities and social sciences, and specifically from the rich and stimulating new field of critical disability studies. Disability studies is eminently interdisciplinary, because disability itself cannot be understood within the bounds of one discipline or method.

We believe that the issue of disability in Australia today urgently merits a public conversation, not simply because it is a matter of

justice for millions of people with disabilities and those close to them; rather, because disability is, more than anything, about ourselves. To understand how our society works and who we are in society, we need to understand the deep implication of disability in our most cherished beliefs and values.

Our understandings of what is normal are shaped by what we unconsciously think is abnormal. How we experience and feel at home, or otherwise, in our bodies is profoundly influenced by the ideas we have about ability and disability. Notions of work and health are bound up with feelings about capacity and lack of capacity. Who may love whom, how we express intimacy with others, and who may reproduce and who may not are all ruled by perceptions regarding disabilities. The apartheid we have created forges disabling structures not just for people with disabilities; such otherness shapes all of us. To make sense of our society we need to understand disability – a task towards which we hope this book contributes.