

The clean and proper body: genetics, stigma and disability discrimination laws

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I was like everyone else — normal, quarrelsome, gay, full of plans, and all of a sudden something happened! Something happened and I became a stranger. I was a greater stranger to myself than anyone. Even my dreams did not know ... what they ought to let me do — and when I went to dances or parties in them, there was always an odd provision or limitation — not spoken of or mentioned, but there just the same.

— Young woman writing about her experience of polio, quoted in Goffman (1986, 35)

The dividing line between the stigmatised and normalised, 'clean and proper', body is integral to law. Disability discrimination laws, even as they set out to offer protection to those defined as disabled, entrench the division between normalised self and stigmatised other, projecting onto the 'disabled' body those abject qualities of incapacity or vulnerability that the privileged normalised body seeks to deny. This seemingly static relationship, however, has the potential to be transformed by the disruptive qualities of the new genetics. Genetic technologies create novel forms of abjection, revealing all bodies as flawed and undermining the fantasy of the clean and proper body. This allows for the possibility of a new approach to disability discrimination laws, based on a more ethical relationship between the normalised and stigmatised body.

Introduction

What is the dividing line between the stigmatised and the normalised body?¹ On the one hand, the divide is treated as if it is impassable; on the other, the smallest incident — 'something happened' — can shift a person from one side of the divide to the other. The possession of a normalised body: inoffensive, contained, law-abiding —

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1 Here I accept Goffman's (1986, 3) definition of stigma as 'an attribute that is deeply discrediting', while noting his point that 'a language of relationships, not attributes, is really needed': stigma is something that happens to people by virtue of their relationships with others, thus I use the term 'stigmatised' in favour of 'stigma'. The stigmatised 'body' of discrimination law also includes stigmas originating in status (such as prior criminal conviction) and states of mind (such as mental illness). A 'normalised' body is one exhibiting the 'complement of attributes felt to be ordinary and natural' for a person in that social category (Goffman 1986, 2).

the 'clean and proper' body² — is an unreliable state and one that must be continually regulated and recreated if the fantasy is to endure.

Genetics plays a role in both creating and disrupting the clean and proper body — and, with the advent of the new genetics,³ possibilities for both pollution and purification have expanded. Manipulating the lines that demarcate categories of selfhood, genetics offers both the possibility of greater regulation of the self and its inevitable disruption. I argue that genetics holds the potential to transform relationships between self and other, by revealing the line between the stigmatised and normalised body as constructed and malleable.

This holds particular promise for discrimination law, which is unique both in its acknowledgement of the stigmatised body and in its attempts to redress the disadvantages imposed upon it. However, discrimination law still relies on and reinscribes the impassable gulf between normalised self and stigmatised other. It projects abjection onto stigmatised others, and emphasises the divide between them and those with normalised embodiment. Discrimination law thus permits those who are not in the stigmatised category to shore up their sense of themselves as 'clean and proper'.

This article re-examines discrimination law using what I argue is the disruptive, and potentially illuminating, aspects of the new genetics. First, I give an overview of Australian anti-discrimination law and its approach to embodiment. Second, I discuss theories of pollution and abjection, and explore how the creation of a 'clean and proper' body projects these qualities onto stigmatised others. Third, I examine the role that genetics is playing in controlling the stigmatised body, even as it inevitably disrupts how such bodies are defined. Finally, I examine a specific case study of disability as the object of genetic attention. I argue that disability discrimination models, when looked at through the lens of theories on abjection and pollution, offer a possibility to shift current legal approaches to selfhood by revealing the artificiality of the line between supposedly normal and disabled bodies. This in turn can provide a platform for an ethical approach to anti-discrimination laws, in which the normalised body acknowledges its relation to the stigmatised body.

2 The 'clean and proper body' is a term I first encountered in Kristeva (1982), a translation of the French 'corps propre'. I have adapted it from its psychoanalytic context for this article, to capture the ideal of a purified (clean) and effectively regulated (proper) body.

3 The 'new genetics' is the term I give to the period since the mapping of the human genome, when genetics has taken on a heightened role in the construction of identity, particularly through public obsession with technologies such as cloning, gene therapy, transgenics and prenatal genetic testing.

Discrimination law and the stigmatised and normalised body

Overview of anti-discrimination law

In Australia, federal anti-discrimination legislation⁴ exists to redress discrimination on the grounds of disability (*Disability Discrimination Act 1992* (Cth)); sex, including marital status, sexual harassment and pregnancy, and dismissal from employment because of family responsibilities (*Sex Discrimination Act 1984* (Cth)); race, including racial vilification (*Race Discrimination Act 1975* (Cth)); and age (*Age Discrimination Act 2004* (Cth)). Each Act has its own variations, but all share a common structure. In order to show unlawful discrimination, an act must first fall within one of the grounds outlined above. It must occur within designated 'public' areas of life, such as education, employment, provision of goods and services, or administration of government programs.⁵ The act must, directly or indirectly, cause harm to the complainant.⁶ Finally, the act must not fall within one of the exemptions or defences under the relevant Act.⁷ In seeking redress for one of the proscribed acts, a complainant must first seek to conciliate the matter with the Australian Human Rights Commission and, if unsuccessful, may then proceed to litigation.⁸

Within the federal anti-discrimination system, disability discrimination laws are sometimes held out as a high-water mark of redressing disadvantage. The *Disability Discrimination Act* attempts to tackle the systemic disadvantage of people with disabilities in novel ways by adding to individual complaints mechanisms a range of broader provisions, allowing for the development of regulatory standards (s 31), guidelines (s 67(1)(k)) and community 'action plans' (ss 59–65).⁹

4 Although this article will focus on the federal legislation, anti-discrimination statutes also exist in each state and territory of Australia, and these cover similar grounds to the federal Acts.

5 In relation to disability discrimination, see s 15 (employment), s 22 (education), s 24 (goods and services) and s 29 (administration of Commonwealth programs) of the *Disability Discrimination Act*.

6 Sections 5 and 6 of the *Disability Discrimination Act* prohibit direct and indirect discrimination.

7 There is a range of exemptions available in each of the Acts for issues specific to that type of discrimination. For example, in the *Disability Discrimination Act*, discrimination is not unlawful in relation to the provision of insurance in some circumstances (s 46) or to the provision of public payphones (s 50).

8 Few complaints make it through this process to final legal determination. See Thornton (2002, 440): 'Only two or three per cent of complaints proceed to formal hearing, representing the most dedicated of complainants and the most obdurate of respondents.'

9 These are plans setting out how an organisation intends to address disability discrimination issues — for example, by increasing its employment of people with disabilities.

There is no doubt that anti-discrimination law has contributed to social change in Australia. It has done so on an individual, systemic and symbolic level. It has given some individuals redress for the harm caused by discriminatory treatment, most commonly in the workplace. At a systemic level, it has given a language to practices which otherwise were publicly invisible;¹⁰ has given legal weight to political struggles against inequality; and has provided some limited scope for broader social change, although this aspect of the legislation tends to be under-utilised.¹¹ The symbolic effects are impossible to quantify but the language of discrimination, equality and rights has permeated the public sphere, raising expectations of favourable treatment within the protected domains.¹²

Despite these advances, the limitations of anti-discrimination law in redressing disadvantage are well documented. The separate grounds of anti-discrimination law force many complainants to artificially separate the unfavourable treatment they experience into grounds that match the legislation, and also to isolate separate incidents that are actionable discrimination out of what may be a general and pervasive sense of, for example, racism or sexism in their lives.¹³ The legislation focuses on individual complaints, making systemic discrimination difficult — sometimes impossible — to tackle. Protection is confined to incidents experienced in pockets of public life, leaving private life, and so arguably the sources of inequality, unexamined.¹⁴ In Australia, it is only in the anti-discrimination and family law arenas that parties are obliged to undertake conciliation before they are permitted access to legal determination. This requirement means that complainants are required to conciliate in an area of law that is particularly sensitive and painful, where they have often suffered psychic harm. Conciliation processes are also confidential, so they cannot be directly used to inform or educate, or to set a precedent for future situations. Even some of the more ambitious aspects of the *Disability Discrimination*

10 This is the case with sexual harassment, prohibited under the *Sex Discrimination Act*, Div 3.

11 For example, indirect discrimination provisions are used infrequently and have in some cases been narrowly interpreted. See Gaze (2002, 329).

12 The link between these is particularly strong in Australia, where, for constitutional reasons, federal discrimination legislation is primarily founded on international human rights conventions.

13 This is not only a personal difficulty, but potentially a legal one: if race-and-sex discrimination, for example, is separated into actions for race discrimination and sex discrimination, the evidence for each may not be sufficient to satisfy the legal requirements of discrimination. See Human Rights and Equal Opportunity Commission 2002b.

14 It is certainly the case for women's equality that, without addressing in some way 'domestic' inequalities, equality in public life is not possible. See Thornton (1999, 758); Human Rights and Equal Opportunity Commission (2007, ch 5).

Act have also been criticised for insufficiently redressing disadvantage: guidelines are unenforceable and the development of standards has been time consuming, and there is concern that they may undermine the provisions of the Act.¹⁵

Discrimination law and embodiment

In spite of these limitations, anti-discrimination legislation remains a unique and in some ways radical acknowledgement of the material conditions of disadvantage (Gaze 2002, 339). Within the legal framework, a framework that elevates objectivity over subjectivity and valorises abstractions such as justice and fairness, anti-discrimination laws occupy an unusual space as they concern themselves with questions of embodiment and materiality in often intimate detail. This is due in part to the fact that so many anti-discrimination complaints inevitably involve bodily characteristics such as skin colour or pregnancy. This is an area of law in which everything from body odour¹⁶ to eating habits¹⁷ might be discussed, and where the most serious bodily incursions, such as sexual assault,¹⁸ and the most minor — a haircut, for example¹⁹ — might be the subject of a complaint.

Nevertheless, the materiality of discrimination law is also quite fragile; as cases are appealed to higher courts, they are increasingly abstracted and disembodied. In discrimination law, once the body is 'lost', the other elements that tend to characterise this area of law — most notably acknowledgement of emotion and psychic pain — also disappear (Thornton 1999, 754–55). Thornton (1999, 756) points out that it is the very qualities that are associated with 'justice' — abstraction, decorporealisation and neutrality — which 'disguise the injustice at the root of the case — that is, the particularity of the harm that led to the search for a remedy'.

15 Standards, once developed, take precedence over the relevant area of the *Disability Discrimination Act*, such as education, employment or transport, and complaints can no longer be brought in those areas as long as the standards are complied with.

16 In *Ball v Morgan*, 2001, Ms Ball argued that she had been denied full access to a swingers club because of her disability; the respondents argued that they had restricted her access because of her body odour and bad language.

17 In *San v Dirluck Pty Ltd*, 2005, a raw bacon and fried egg sandwich that the complainant ate at work became a source of ridicule and one of the issues on which she claimed she was sexually and racially discriminated.

18 *Lee v Smith*, 2007.

19 In *Trindorfer v Commonwealth of Australia*, 1996, a male employee of the Royal Australian Air Force made a complaint of sex discrimination when he was required to cut his hair, while female employees could keep theirs long.

The 'appearance' of the body and materiality in discrimination law also have complex and contradictory effects, sometimes leading to more subtle and empathetic judgments, and sometimes reinforcing stereotypes and injustices (O'Connell 2008). For example, the focus on the 'sexual' element of sexual harassment has meant that in these cases women's bodies appear as an array of breasts, legs and buttocks, with discussion centring on whether certain ways of touching women are sexual enough to satisfy the legal requirements of sexual harassment. In this area, the way that bodies appear does not improve on the way that women's bodies may be misrepresented in other areas of life, and can unwittingly reinforce the very sexualisation that the law purports to protect against.

When the body and affectivity are acknowledged in discrimination cases, it is the physical and emotional state of the *disadvantaged* party, generally the complainant, that is relevant.²⁰ It is the stigmatised body that is made to 'wear' embodiment: the normalised body remains clean of bodily flaws and vulnerabilities. While acknowledging embodiment means that discrimination law is grounded in the reality of daily life, the one-sidedness of the acknowledgement reinscribes the relative privilege and disadvantage of the parties.

There is also no relationship permitted between the two: it is as if social disadvantage happens on its own with no correlating privilege. Gaze (2002, 336) writes that privilege in discrimination law is 'repressed' because of the desire of those enjoying social advantage to believe that it is earned or based on merit, rather than part of a social system that advantages some at the expense of others. By locating the cause of social disadvantage in the bodies of stigmatised individuals — it is what is 'peculiar' to a woman's body that makes her subject to sexual harassment; it is the possession of a certain skin colour that makes one subject to racial discrimination — the socially advantaged are purified and permitted the fantasy that their privilege has no connection to others' disadvantage.

The acknowledgement of bodies and materiality is one of the most promising aspects of discrimination law: it permits the possibility of genuinely 'seeing' the other, rather than losing real bodies to abstractions. However, the one-sided nature of the acknowledgement of embodiment and the disconnect between the stigmatised and normalised body mean that the privileged can repress those aspects of themselves that might be contributing to social disadvantage. A key to realising the most promising

20 *McLeod v Power*, 2003 is one of the few cases in which the respondent's body is the focus of the case; this is because, I would argue, the respondent was in the unusual position of being the more socially disadvantaged party.

aspects of discrimination law lies in revealing how the distinction between self and other is managed: why some bodies are stigmatised and whether the demarcation between 'normalised' self and 'stigmatised' other can be challenged.

Clean and proper bodies

In the making of a clean and proper body, stigmatising qualities must be discarded; the creation of stigmatised bodies therefore relies on the corresponding construction of clean and proper, normalised bodies. Stigma is not — although it may sometimes appear to be — a universal quality possessed by certain individuals. However, stigmatised states of embodiment are treated in law as if they are individual characteristics, unchanging over time. Below I will argue that in fact recent biotechnologies, specifically genetic technologies, are altering perceptions of embodiment in ways that potentially undermine the regulated line between stigmatised and normalised embodiment. Through the writings of those with marginalised bodies, we see an image of a different kind of self, one which I would argue is more rich and complex, does not require repression/oppression of another, and is also an alternative which genetics has the potential to reinforce and develop.

The fantasy of the clean and proper body

What are the origins of stigma? Goffman (1986, 1) points out that the stigmatised individual is 'a blemished person, ritually polluted'. Anthropologists and psychoanalysts give a perspective on what such a form of pollution might entail. Douglas (1991) investigates the idea of pollution as it applies in a range of societies, and discusses how purity is maintained through societal and individual control of the polluting aspect. She points out that pollution, or dirt, is 'matter out of place', contingent on the infringement of a system of ordering: the polluting element is that which does not fit within the ordering system, or which exists on its margins and so threatens the borders that maintain the system (Douglas 1991, 36).

While Douglas focuses on societal pollution rituals, Kristeva (1982) approaches pollution from a Freudian psychoanalytic perspective, outlining a theory of abjection in which she argues that a precondition of being a person with full selfhood in the social order²¹ is the possession of a clean and proper body (see also O'Connell 2005). What is abject about the body, what triggers disgust and horror, includes aspects of ingestion, waste, death and sexual difference. Kristeva's account emphasises the

21 Kristeva's term for this is a 'speaking subject', emphasising the acquisition of language as a precondition for such a status.

importance of an effective regulation of body boundaries: what is abject must be continuously rejected and expelled; body boundaries must be constantly regulated, including by social taboos such as those surrounding menstruation or eating, and by law (See also Freud 1950; Douglas 1991, ch 3).

Important in these accounts is the idea that what is rejected about the body can never be permanently banished (Grosz 1989, 70). It can only be temporarily held at bay through regulatory work that is continuously undone. Clean bodies rely not only on this effort, but also on an abiding and child-like pretence: that dirt and waste, if hidden away, do not exist; that disease, disability and death are under human control. Since these qualities must be denied, they are often hidden away in other people: Butler (1999, 69) calls the 'abject' that which has 'literally been rendered "Other"'. For example, bodies that are understood as 'disabled' carry, for all bodies, the burden of what is in fact a generic human fragility — a common susceptibility to disease and accident. Bodies that confound the boundary between one bodily state and another, such as those that are pregnant or in the throes of a transient illness, also undermine the fantasy of the clean and proper body, since they illustrate the indeterminacy of body boundaries (Shildrick 1997). Each of these categories of embodiment then represents a visible manifestation of the qualities that must be kept at bay for 'normalised' bodies to maintain their status: they therefore invite greater scrutiny and increased regulation.

An alternative view of the improper body

How does this fantasy look from the perspective of those possessing stigmatised bodies? On one reading, Douglas and Kristeva present a view of social and individual pollution that seems to leave little room for change, embedded as the stigmatising process is to the formation of selfhood and society. Yet it is important to remember that they also present stigma as socially and individually constructed, a fantasy capable of deconstruction.²² The way that bodily indeterminacy is experienced, acknowledged and built into relationships is neither universal nor inevitable.²³ This is clear from the writings and self-descriptions of feminists and disability theorists,

22 Hyde (1997, 214), discussing Kristeva's psychoanalytic approach, writes that it attracts him because it 'captures this middle ground of construction that are biologically based but not biologically inevitable'.

23 Psychological work also demonstrates that stigma itself is not experienced universally as negative, nor are stigmatised people responded to in singularly rejecting ways. 'Thus current views on stigma, from the perspective of both the stigmatiser and the stigmatised person, consider the processes of stigma to be highly situationally specific, dynamic, complex and nonpathological': Heatherton et al 2003, 2.

who give an alternative view of the improper body, one that emphasises what is positive, rich and creative in possessing a body that defies conventional body boundaries (O'Connell 2005).

Many feminist writers, from Beauvoir (1989, first published 1949) to contemporary cultural theorists (Bordo 2004), have described the way that women's bodies, marked as different or Other, deny them the position of neutrality accorded to men, the 'modest witnesses' described by Haraway (1997). Women's bodies are biologically excessive and in need of regulation: they bleed, lactate, produce vaginal secretions, swell with pregnancy and give birth (Mykitiuk 1994, 86). This biological excess is also true of other stigmatised bodies, such as the disabled body, which is viewed as 'either deficient or as profligate' and therefore 'ungovernable, intemperate, or threatening' (Garland-Thomson 2002, 1).

Yet, rather than responding to the experience of stigma simply by internalising its negative judgment, strands in both feminist and disability studies 'resist popular accounts of suffering and self-hatred' and disrupt negative expectations of what it means to have a disability (Herndon 2002). In this disruption, a gap is opened between internal and external judgments on possessing a stigmatised body. Garland-Thomson (2005, 1568) writes that the 'narrative of abjection' in the lives of people with disabilities is an externally imposed negativity which 'identifies disability as that which one can and must avoid at all costs', rather than 'an integral part of one's embodiment, character, life, and way of relating to the world'.

Grealy (2004), for example, writes first of the shame that resulted from others staring at her face, misshapen by bouts of cancer and unsuccessful reconstructive surgery, making even simple interactions impossibly painful. Of one conversation with a new acquaintance she writes:

Out of nowhere, came the intense feeling that he shouldn't be looking at me, that I was too horrible to look at, that I wasn't worthy of being looked at, that my ugliness was equal to a great personal failure. [Grealy 2004, 185.]

But Grealy's youthful experience of her 'disability' gradually gives way to a realisation that her experience of herself as abject is based on an image that can be distinguished from her internal experiences: 'As a child I had expected my liberation to come from getting a new face to put on, but now I saw it came from shedding something, shedding my image' (Grealy 2004, 185). In other words, for Grealy the sense of a horrible excess moved from being located in her body to being external to her.

Women, particularly women writing about their disabilities or their race, do not describe a 'clean and proper' body; in fact, out of this literature comes an alternative view of abjection that is highly conscious of disrupted body boundaries, of the shifting internal/external nature of the experience of abjection, and more tolerant of its inevitable existence. Women, in this alternative view, describe themselves in terms that emphasise not purity or rigidity, but fluidity and multiplicity.²⁴ The pregnant woman is a clear example of the fluidity of body boundaries and the fact that selfhood is a process worked out in relation with others, rather than a mantle assumed and worn to the grave, and theorists taking this alternative view have not only acknowledged this, but celebrated it and used it as the basis for their work (Karpin 1994; Savell 2002).

Genetics as pollutor and purifier of the body

When Douglas wrote *Purity and Danger* in 1966, she felt able to assert that 'primitive' cultures were more pollution prone, while in 'modern' cultures the sense of pollution was mostly superficial, a 'matter of aesthetics, hygiene or etiquette' that 'may create social embarrassment' (1991, 74). While that was a debatable claim even at the time Douglas was writing, contemporary developments in biotechnology and embodiment have rendered her statement false. Biotechnologies of the body, I argue, have shown that in contemporary Western cultures, the disruption of body boundaries through technological incursions is dangerously polluting. Yet the disruption that genetics makes to identity has a lot in common with alternative views of selfhood and also can be used as a means of analysing and undermining stigma.

Genetics controlling the improper body

Genetic technologies such as cloning, transgenic technologies, reproductive technologies and other genetic manipulations seem to give unprecedented control over what Haraway (1997) calls 'Life Itself'. A classic statement of this is made by the United States President's Council on Bioethics (2003, 1), which writes that biotechnology is 'a form of human empowerment':

24 Irigaray (1985, 26) says (italics in original): '*She is neither one nor two*'. Zora Neale Hurston describes herself as 'a brown bag of miscellany' (cited in Harris 1990, 613). Williams (1991, 183) writes: 'I hold myself tightly and never spill into the world that hates brown spills.' See also Martin (1992), who contrasts medical language with women's self-descriptions of their bodies.

By means of its techniques (for example, recombining genes), instruments (for example, DNA sequencers), and products (for example, new drugs or vaccines), biotechnology empowers us human beings to assume greater control over our lives, diminishing our subjection to disease and misfortune, chance and necessity.

Genetics holds out a unique contemporary promise that the dangers of polluting disease and disability will be overcome and that the 'improper' body will finally be under human control.

Genetic technological attention closely follows those areas of social and bodily pollution identified by Douglas (1991) and Kristeva (1982): food, disease, death and reproduction. Transgenics evokes the prohibitions of Leviticus by creating food that 'does not conform to its class' (Douglas 1991, 74), disrupting the boundaries between types of food by transferring DNA between categories of plant or animal, and disturbing the belief that distinctions between species are inviolable. The identification of genes for heritable diseases and the development of genetically individualised medicine promise new attacks on the most intransigent diseases. Cloning offers a future in which death may be postponed by replacing body organs as they fail. Prenatal genetic diagnosis offers greater certainty of fetal health and viability in the face of the genetic lottery of reproduction. The clustering of genetic attention around those issues that are most sensitive to abjection appears to give genetic technologies enormous power over the most polluting elements of selfhood. Disease and death can be staved off, the unpredictability of reproduction brought into the arena of rational choice.

However, biotechnologies, including genetic technologies of the body, are inherently transgressive because through them we interfere with, and so transform, the raw material of what we call 'nature'. By this, we change the natural order and make new forms of life and artefact. The pleasure and comfort of controlling the polluting elements of personhood are undermined by the fact that as we interfere with all that is most 'natural' about embodiment, new forms of pollution inevitably result. Once we start playing with the boundaries of embodiment, it is impossible to continue to assert that the body is a closed system. In learning how to control body boundaries, geneticists inevitably shift them, producing anxiety, horror and disgust. The very act of technological control undermines itself.

The gene as disruptive agent

The gene has particular intensity as a disruptive agent. It is spoken of as the most fundamental element of human life: a building block, a blueprint, the book of life (see, for example, Kay 2000). These metaphors imply not only that the

gene is the essential material of life, but also that the genome is a set of endlessly constructible units. It is this constructive element that gives genetics its seeming capacity to 'purify' bodies of disease and disability. On the other hand, it is also this quality that disrupts and disturbs the fantasy of a purified autonomous body. A kind of feedback loop establishes itself: as genetic technologies are employed to control the body, they inevitably reveal it as changeable, non-static, potentially malleable; in this, as Waldby (2000, 7) puts it: 'Any fantasy of organic integrity ... is lost.' The genetic body is a set of processes that can be 're-engineered' (Novas and Rose 2000, 487). This lack of boundaries, the unnaturalness that is revealed, in turn triggers anxiety and further technological intervention to reassert control.

The gene is also increasing its incursions into social relationships, taking on increased cultural currency, along with its biological significance (Nelkin and Lindee 1995; Franklin 2001, 251), and its effects are felt across ever-widening arenas of life, from medical and legal practice, to citizenship and family relations (Waldby 2001, 781). Waldby (2001, 781) refers to 'relentless social geneticization' in which 'direct, personal encounters with genetic practice are becoming inescapable'.

Given that the gene is continually described as a fundamental agent of life, and has ever-increasing social significance, the disruptive powers of genetic technologies are acute. They conjure up a 'world turned upside down' in which all manner of disruption seems frighteningly possible: animals and plants are no longer contained within their species,²⁵ 'subhuman' beings are created²⁶ and babies are 'made' not born (Franklin and Roberts 2006).

With the fears that such disruptions trigger, law is called upon to set limits on genetic technologies. The more 'unnatural' the interference, the more likely it is to attract legal regulation.²⁷ Karpin (2006) has pointed out that in this area, law sometimes imagines into existence new forms of embodiment, for the sole purpose of regulating them — as with Australian anti-cloning legislation, which makes 'chimeras' and embryos of same-sex parentage unlawful (*Prohibition of Human Cloning Act 2002* (Cth), ss 13 and 15, now *Prohibition of Human Cloning for Reproduction Act 2002* (Cth)). As I discuss below, law is also called in to regulate areas in which genetics is simply

25 The transgenetic manipulation of plant and animal species for food production allows species to be 'mixed'.

26 Cloned humans are sometimes imagined as beings of lower biological status than genetically unique individuals — a 'slave' species in the making. See Smith (1983, 119).

27 A good example here is human cloning, which is unlawful in Australia. See the *Prohibition of Human Cloning for Reproduction Act 2002* (Cth).

disrupting settled legal and social ideas, where there is little or no evidence of any harm to be remedied.

Genetics controlling and disrupting the disabled body

For those with stigmatised embodiment, genetics in its purifying aspect seems only to magnify the desire to 'undo' whatever is improper about their bodies, and to realise the fantasy that 'it is possible, by means of human actions, to have the bodies we want and to avoid illness, disability and death' (Wendell 1996, 9). There is the further possibility, which Lippman (1991, 45) alludes to, that increasing genetic knowledge will lead to a more rigorous definition of disability; in the increasing scrutiny of the embryo, there is the prospect that any and all disabilities will be viewed negatively. Garland-Thomson (2002, 16) sees, writ large, the negative impacts of genetics in its purifying role, writing that the 'popular utopian belief that all forms of disability can be eliminated through the prophylactic manipulation of genetics' is 'potentially eugenic' and will inevitably increase prejudice and discrimination against people with disabilities.

When people with disabilities have attempted to use genetic technologies in ways that embrace their forms of embodiment — what Karpin (2007) terms 'negative enhancement' — for example, to fulfil a desire for a child with a particular disability, such as deafness, they have met with both a disgusted public response and regulatory hurdles. In Australia, parents cannot use pre-implantation technologies to satisfy their preference for a child with a disability; National Health and Medical Research Council guidelines permit pre-implantation genetic diagnosis only for the purpose of avoiding disability (NHMRC 2007 12.2).

In these approaches, the commonality of disability is entirely displaced. Disability is stigmatised, in part, *because* it is a manifestation of the vulnerability of all human bodies to accident, disease and age; disability, even narrowly construed, is a state of being that most people will experience at some point in their life.²⁸ Yet there is always the temptation to deny this vulnerability and to consider the disabled body as irredeemably and permanently Other.

While genetic technologies are being used as a means to eradicate disease and disability, they also show that we are all the bearers of biological 'flaws'. As genetic

28 As well as illness or accident, ageing is likely to bring with it the experience of disability. In Australia, 51 per cent of people aged 60 or older have a disability, and these figures increase sharply with time: Australian Bureau of Statistics 2003, 3.

scientists continue their work on the human genome, more and more diseases are being linked to their biological bases, and the technologies for identifying individuals 'at risk' are entering daily life (Novas and Rose 2000). Further, genes 'for' a range of latent abilities, disabilities and behaviours are being identified. Genetics reveals that '[d]isease, disability and even death are not miraculously absent from some bodies, inhabiting only the disabled body' (O'Connell 2005, 228), and that all bodies are inescapably affected. Rather than thinking of certain groups as 'able-bodied', it is more accurate to think of them as 'not-yet-disabled', and genetic knowledge challenges us with this fact.

Disability and genetic discrimination

Law protecting the normalised body from genetic disruptions

When genetics seems to undermine the normalised body, it invites legal regulation. In Australia, as in the United States and other Western countries, developments in genetic science have fuelled legal moves to protect the able-bodied from any potentially negative effects of genetic technologies by strengthening privacy laws,²⁹ conducting inquiries into genetic discrimination and instituting human rights protections.

In Australia, the earliest legislative proposal was for a separate Act tackling both genetic discrimination and privacy, the Genetic Privacy and Non-discrimination Bill 1998 (Cth). While this Bill was not passed (it was proposed by a minor party), the federal government responded to concerns over genetics with a reference to the Australian Law Reform Commission, requiring the commission to report on potential law reform in the areas of genetic privacy and discrimination (Australian Law Reform Commission 2003). More recently, a human rights Bill for Australia has been drafted by a non-government organisation, containing a declaration of rights relating to the human genome (Human Rights Bill 2006 (Cth), s 13). These legislative proposals are aimed in part at addressing the fears of able-bodied people about their possible future stigmatisation. For example, the desire to extend privacy protection over genetic information can be seen as an attempt to keep 'secret' any information that would stigmatise the otherwise able-bodied bearer of flawed genes (Petschler 2000, 10).³⁰

29 The *Privacy (Private Sector) Amendment Act 2001* (Cth) regulates, among other things, the storage, management and disclosure of health and genetic information.

30 On the problems with using a privacy model to protect genetic information, see Karpin 2004.

It is permissible to discriminate against people with disabilities when offering insurance (*Disability Discrimination Act*, s 46), because additional risks are seen as a valid consideration in underwriting insurance products (Australian Law Reform Commission 2003, 26.3). However, the extension of such permissible discrimination to those who have not yet manifested a disease or disability is obviously unsettling for those who would never have expected to be included in this category. The Australian Law Reform Commission (2003, 26.3) called the possibility of genetic differentiation between individuals for the purposes of insurance ‘a principal factor underlying the establishment of this Inquiry’. Rather than face the possibility of future discrimination, there is a clear preference for genetic information to remain locked in the body. Privacy laws are typically modelled to give greater control to individuals over the use, storage and disclosure of personal information. In relation to genetics, such laws are appealing to those who fear the ‘secrets in their genes’ and do not want them revealed.

The desire to create legal protections against genetic harm is particularly interesting given that there is so little evidence of any existing harm. For example, despite the intense concerns about discrimination in insurance, there have been no cases claiming redress for such discrimination.³¹

Genetic discrimination and the Disability Discrimination Act

The push for further regulation of personal genetic information is particularly striking given that the *Disability Discrimination Act* already covers genetic discrimination. The definition of disability encompasses an extensive list of bodily effects, disorders and malfunctions, as well as any past, future or imputed disability. Although the impact of the Act has been limited in other ways (Rattigan 2004), this broad definition of disability has been generously interpreted.³² Bassler and Jones (2002) point out that

31 Researchers providing information to the Australian Law Reform Commission stated that they had identified 43 cases in which individuals claimed to have been discriminated against by insurance providers on the grounds of genetic status (but had brought no legal action). However, the case studies they provided seemed to be cases of permissible discrimination — that is, cases in which the genetic status of the individual was a relevant factor. It is unclear, therefore, how many, if any, cases of unlawful discrimination have occurred: Australian Law Reform Commission 2003, 26.20–26.33.

32 In fact, the breadth of the definition has been controversial. In *Marsden v HREOC and Coffs Harbour & District Ex-Servicemen and Women’s Memorial Club*, the Federal Court of Australia found that this definition of ‘disability’ extended to drug dependency. In response, the federal government proposed a legislative amendment explicitly removing drug addiction from the definition of disability: the Disability Discrimination Amendment Bill 2003 (Cth). The Bill subsequently lapsed.

this definition of disability allows the *Disability Discrimination Act* to focus on the social limitations imposed on people with disabilities, instead of on the medical status of the individual. In other words, the *Disability Discrimination Act* 'locates the barriers to inclusion in the social fabric and structures of society', rather than in the body of the individual with a disability (Basser and Jones 2002, 262).

Such a broad definition clearly covers genetic disorders. In fact, many cases under the *Disability Discrimination Act* could be classed as 'genetic discrimination' because of the number of disabilities that have some genetic cause. For example, in *Trindall v NSW Commissioner for Police*, 2005, a police officer was put on restricted duties after his managers became aware that he had sickle cell trait, a genetic blood disorder in which a portion of red blood cells contain abnormal haemoglobin. The court found that he was discriminated against on the grounds of his disability, because of both his restricted duties and the fact that he was required to produce medical evidence in order to have them lifted.

Trindall, however, concerned a genetic disorder that was manifest, because the officer had a measurable blood abnormality, although asymptomatic. 'Genetic discrimination' is generally used to mean discrimination against people who may have a genetic flaw but it has not yet manifested — in other words, the able-bodied. These too are covered by the *Disability Discrimination Act*. Although there have been no reported cases of genetic discrimination in Australia, there has been at least one complaint,³³ in which an inmate was required by the Parole Board to undergo testing for Huntington's chorea before his application for release would be considered (Human Rights and Equal Opportunity Commission 2002a). The disease, for which the complainant was at risk, can be accompanied by loss of mental capacity and anti-social behaviour, and the Parole Board argued that it would not release the complainant if he were so affected. The complaint was heard under the *Disability Discrimination Act*, but no conciliation was reached and the complaint was terminated.

A remedy, therefore, already exists under the *Disability Discrimination Act* to protect seemingly able-bodied people from unfavourable treatment on the basis of their

33 Another complaint of disability discrimination in employment involved the use of genetics as a 'defence'. In this case, a woman was denied a job after she revealed in a medical examination that she had suffered enuresis (bed-wetting) until the age of 14. Her employer argued that this was indicative of psychological disturbance. The woman produced evidence that other family members had experienced the same condition, and that it was therefore genetic and not indicative of psychological disturbance. The complaint was terminated as unconciliable and did not proceed (Human Rights and Equal Opportunity Commission 2002a).

genetic characteristics by including them in the definition of disability. The existence of this legal protection has not prevented a high degree of anxiety around the potential for able-bodied individuals to be discriminated against on the grounds of their genetic status. Given that there have been no reported cases of genetic discrimination and that the existence of unreported incidents of discrimination is questionable,³⁴ the degree of public concern over genetic discrimination has been unprecedented. Other areas of anti-discrimination law have taken decades of activism and overwhelming evidence of persistent and systemic harm to receive legislative protection. I would argue that the motivation for legal regulation of personal genetic information is largely driven not by an actual need for protection, but by a need to maintain the definitional boundaries between the able-bodied and the disabled — in other words, between the normalised and stigmatised body.

‘Welcome to the club’: welcoming in disability

Although issues of genetic discrimination [raise] images of Aldous Huxley’s *Brave New World* in its most sinister sense, I have to say — at the risk of overworking my metaphor — that the newly discovered, uncharted territories of this harsh new continent, too, are ones where some of us have been living for a considerable time.

So one possible response from people with disabilities to concerns from people who do not have a disability yet but are worried by possible genetic discrimination on the basis of a disability they may develop in future would be a fairly unsympathetic ‘welcome to the club’. [Innes 2000.]

Basser and Jones (2002, 265) state that in order to have their human rights protected, people with disabilities need to ‘escape from the iron cage of the deficit model’, which located fault in the body of the disabled person, rather than in the society that excludes them. They argue that there are three dimensions of response necessary to ‘operationalise’ the human rights of people with disabilities and that these are already contained in the *Disability Discrimination Act*. These dimensions are first, the system of individual complaints; second, the provisions for tackling systemic discrimination through standards and guidelines, which represents the state working alongside people with disabilities; and third, provisions for community involvement in taking responsibility for disability discrimination through action plans.³⁵ This last stage treats the inequality of people with disabilities as a community problem and takes a partnership approach to its solution (Basser and Jones 2002, 283).

34 See above, note 31.

35 See above, note 9.

However, I would argue for a fourth step to overcoming disability discrimination: not only that the community take responsibility for the inclusion of people with disabilities into society, but that those who are not-yet-disabled recognise the need to include disability into their own self-perception. This step is not necessarily dependent on law reform: the *Disability Discrimination Act*, with its broad definition of disability, already embraces the not-yet-disabled. Yet the meaning of any law is dependent on the social context in which it is embedded, and social acceptance of the commonality of disability has lagged behind legislative change. Without this social shift in thinking about disability, the desire to maintain the boundary between the stigmatised and the normalised body can make discrimination law a tool of reinscribing disadvantage rather than redressing it. Maintaining this boundary means continuing to locate disadvantage in the body of the disabled person: a perpetuation of the 'deficit' model.

Following Derrida and Dufourmantelle (2000), this dimension could be termed 'welcoming in' disability. 'Welcoming in' is an approach to what is excluded that is proposed by philosophers of deconstruction. Cornell (1992) calls deconstruction 'the philosophy of the limit' and she offers a reading of postmodernist philosophy, and of Derrida specifically, that undermines both the seemingly closed 'normalised' body and its fantasised separation from the stigmatised other. Cornell's jurisprudence focuses on the boundaries of systems of thought, including law, and presents deconstruction as an explicitly ethical philosophy (when it is often derided for its supposed nihilism) because, along with revealing the limits of law, it is attentive to what has been excluded or rejected by that system.

Another way of putting this is to say that deconstruction is concerned with what is expelled, laid waste and made abject by any particular system of thought. Cornell (1992) refers to 'the *Chiffonier*', the rag-and-bone man who gathers and reinstates to value what has been discarded by others — a metaphor for the intellectual and ethical task of deconstruction.³⁶ The ethical stance suggested by Derrida and Cornell is not a simple solution to the creation of stigmatised otherness. As long as there are systems of thought, there will be exclusions and otherness (Cornell 1992, 70). What can be created is not a perfectly inclusive system, but one that is in a constant struggle to acknowledge the 'remains'.

36 Cornell has borrowed the concept of the chiffonier from Walter Benjamin, who in turn is indebted to Levi-Strauss's concept of *bricolage*, derived from the *bricoleur*, who makes and mends new objects from bits and pieces of old ones. However, Cornell adds human and ethical elements to the metaphor: the rag-and-bone man collects human refuse — what humans have actively decided is garbage — and affords it value.

Douglas (1991, 163) has written that in pollution — in the remains — is also creative power and potential, while purity 'is the enemy of change, of ambiguity and compromise'. Purity is inevitably linked to rejection and so, she argues, 'when purity is not a symbol but something lived, it must be poor and barren' (162). Since we can never genuinely expel what exists in our own bodies, the violence that is done by investing stigmatised bodies with the qualities of abject otherness is also done to ourselves. Thus, both the normalised and the stigmatised bodies are reduced by the creation of abject otherness. The disadvantages for people with disabilities are concrete and ubiquitous: from fewer opportunities for work, to limited access to services that other citizens take for granted, to lower social and financial status. What is lost for the not-yet-disabled is the 'loss' that can accompany privilege — not comparable in any way, but a loss nonetheless. It is the loss of a way of experiencing embodiment that is free from the anxiety of self-regulation and the hostility towards supposedly abject otherness: a 'poor and barren' state.

It is genetics that currently presents the challenge to our ideas of disability that makes it possible to see disability discrimination laws outside of the normalised/stigmatised 'trap' that perpetuates the deficit model. The new forms of abjection created by genetics offer an opportunity to reconsider traditional conceptions of bounded selfhood and welcome in the stigmatised other. Like the alternative view of selfhood I outlined above, the disruptive aspect of genetics presents embodiment as fluid and malleable, and offers the possibility of seeing stigmatised otherness in all bodies. The limit of our system of thought about disability is the line that distinguishes between able-bodied and disabled. Genetics reveals that line to be a construction, by opening up the possibility that we contain future or non-manifest disabilities in our genes. Genetics makes real and unavoidable the legal point that future, potential or imputed disability *is* disability. At the very least, on genetic conceptions of the body, disability hovers within all bodies. When Innes says 'welcome to the club', he is introducing the not-yet-disabled into the society of people with disabilities: the place where genetics has shown us we all already belong. ●

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