FROM BLACK BOX TO 'OPEN' BRAIN Law, Neuroimaging and Disability Discrimination

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The brain is commonly thought of as a bounded and private organ of selfhood - a repository of individual thoughts and ʻblack box' closed against contemporary neuroimaging technologies seem to open the brain to scrutiny, offering a selfhood that is increasingly transparent, knowable and manipulable. On one view, this recasts the brain as a site of potential regulation, subject to the language of self-discipline, law and medical intervention. Yet there is also a disruptive element to these technologies, as they reveal the brain to be embedded in overlapping biological, social and environmental systems, interdependent and in constant change over time. This article considers significance of these developments for law, with particular reference to the construction of disabled identity and the brain in discrimination law. Will this sense of openness in the brain merely provide opportunities for increased medical regulation, in which law is bypassed, and neuroimaging technologies facilitate the identification of risk in individuals and mitigation of that risk through neurochemical and other brain interventions? Reading these technological developments alongside current theories of disability and neurodiversity, this article offers an alternative view of legal selfhood in which the brain is neither a black box nor an object to be screened and controlled, but open in a more radical sense, inseparable from its functioning the body and environment, constituted by constitutive of the Other.

A popular metaphor for the 'old' brain is a black box: a recording device that shuts away memories, experiences and dreams, and reveals its contents mysteriously and unreliably. On this view of the brain, identity-formation happens in the context of a deep and possibly unknowable interior life. Yet as brain screening technologies such as functional magnetic resonance imaging (fMRI), which maps brain function through scanning changes in oxygenation levels, are integrated into our sense of biological selfhood, the brain has come to be seen as open to examination and interpretation by

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experts. These technologies present a fundamental disruption to the black box model and an urgent intellectual moment in which the relationship of the brain to identity and to social institutions such as law may be reconsidered.

In place of the black box, there are two emerging models of a brain-based identity: a narrowly individual 'control' model in which the brain is regulated through screening and biological intervention, and an 'open' model that situates the brain in its environment and in relationship to others. I argue in favour of an open model, in which the brain is inseparable from its functioning within the body and embedded in overlapping biological, social and environmental systems. On this view, new brain technologies invite us to acknowledge that we are always constituted by and constitutive of the Other. With the open model, the brain is viewed in a temporal and relational context, always becoming, and interdependent with its surrounding and overlapping systems. The radical openness and interdependency that is a possible view of the 'new' brain suggests a new kind of ethics that flows from this revised selfhood.

It also suggests new possibilities for law. In disability discrimination laws, which deal intimately with identity and the body, law has some precedent for a regulatory model that acknowledges the interaction of social institutions, communities and individual biology in shaping identity. This article considers each of the brain models – black box, control model and open brain – and their implications for law, with reference to Australian disability discrimination laws and a group of people who define themselves as neurologically 'diverse' rather than disabled, and who might be expected to benefit from a more expansive approach to brain-based identity.

The Black Box

Throughout the past century, the idea of a deep interior space was a commonplace of culture and society. The competing disciplines of psychiatry, psychology and psychoanalysis helped to establish and entrench this idea, both indirectly through the conflicts and dissonance in the burgeoning industries of self-knowledge, and directly – for example, through psychoanalytic ideas of selfhood. At the heart of psychoanalysis was the idea that perfect self-knowledge was never achievable, but rather an ongoing effortful process of work and exploration. An unruly interior – with layers

As Rose (2007), p 26 puts it: 'Throughout the first 60 years of the twentieth century human beings came to understand themselves as inhabited by a deep interior psychological space, and to evaluate themselves and act upon themselves in terms of this belief.'

Each of these disciplines also contains within it an enormous diversity of approaches and beliefs. A classic example lies in the divergences between Freudian, Jungian, Lacanian and Kleinian psychoanalysis.

For example, Freud's description of the repressed impulse sees such impulses as struggling towards consciousness but being internally censored and only breaking through into conscious mind indirectly, through the passage of dreams or other indirect means, via the use or misuse of memories. Grosz (1990), p 87 writes: 'The unconscious wish

and subterranean currents of which we are dimly or fleetingly aware, fuelled by subconscious drives and desires – was a crucial component of our sense both of depth and of mystery. These depths of mind, making us fundamentally unknowable, were also crucial to our sense of a private self, since what is unknowable is also untranslatable.

Along with this idea of the mind-brain as mysterious and unknowable came an image of the brain as structurally unchanging, a kind of container for the contents of the mind. This offered a sense of boundary and a barrier against incursion. Thoughts, dreams and desires – albeit fragmented and contradictory – were ours alone, to share or to keep 'inside'. Law's role in boundary-keeping has ensured that it has an expected role to play in protecting the mind's 'container', specifically through reiterating and shoring up a distinction between public and private life, a role that traditionally has shielded the internal domain from regulation.4 In addition, this legal role is crucial to the perpetuation of the liberal subject, the autonomous individual who is literally 'self-contained'; a self-in-a-box, surrounded by other boxed selves who, whether familiar or strange, are all shut off and fundamentally unknowable. This bounded view of the brain, and therefore of the self, is under threat, but it nevertheless persists in political, economic and popular discourse, as well as in law, where we may be thought of as 'lords of our tiny, skull-sized kingdoms, alone at the center of all creation'.5

I am calling the deeply entrenched idea of a bounded, mysterious brain the 'black box' approach. A black box is a metaphor of known inputs and outputs passing through a bounded, shut-off interior. The black box is a commonly employed metaphor for the structurally static, but mysterious brain. Reid and Baylis, for example, refer to the 'Decade of the Brain' in the 1990s, as 'an effort to shed light into the "black box" of the human brain'. It is also employed as a container metaphor to locate our human vitality and intellect in the physical brain. The brain of physicist Stephen Hawking, who has motor neurone disease, is described by a *New York Times* journalist as 'a pinging black box amid the physical wreckage'.

The brain as black box has an ethical application beyond its significance for medical or legal selfhood. Butler claims that our unknowability is a foundation for an ethical relation to others, since

reactivates a memory (either recent or infantile) which will serve to express or represent it in the manifest dream. This may enable it to gain a (compromised, disguised) access to consciousness.'

The distinction between regulated public and unregulated private life has long been a target of criticism by feminist legal scholars. O'Donovan (1985), p 9 writes that: 'The elaboration in legal discourse of a private domain of subjectivity, morality and the personal as "not the law's business" has inevitably led to non-intervention in domestic life.' See also Fineman and Mykitiuk (1994) and Thornton (1995).

⁵ Wallace (2009).

⁶ Reid and Baylis (2005), p 21.

⁷ 'Many Kinds of Universes, and None Require God' New York Times, 7 September 2010.

affirming what is opaque and unknown in one's self 'may allow one to affirm others who may or may not "mirror" one's own constitution'. In other words, by being forced to acknowledge that we are strangers to ourselves, we are ethically primed for accepting otherness; the stranger within orients us to the stranger without. The failure to give a full account of ourselves marks us in a relation of humility to others, since we cannot present ourselves to them in full self-knowledge, and we must therefore forgive those 'who are also constituted in partial opacity to themselves'.

The shared strangeness of being that Butler identifies is one possible source of ethics, but not the only one. For the purpose of this article, the question is: If we lose our sense of unknowability, what other prompts to an ethical relation will shape relations with the Other? This question arises because ethical uncertainty about ourselves, the incoherence and unknowable depths of our interior selves, is under threat from new ways of thinking about the brain and the self, triggered in part by neurological technologies such as brain scanning and associated interventions.

Unlocking the Box

Into the 'black box' vision of the brain comes the incursion of visual technologies and their computer-aided imaging, making the body more open to scientific representation and appraisal. Heightened public interest in the brain in particular has been triggered by the increasing use of brain imaging technologies, most commonly fMRI. This procedure measures changes in the oxygenation of blood made by neurons as they activate and consume oxygen. It is an indirect measure of brain activity, in which researchers can make inferences about brain processes by analysing a continuous set of images recording brain activity, collected at a rate of every few seconds over a period of half an hour or more, while the screened participant undertakes a directed activity. The resulting pictures of the brain, lit up with artificial colour, are constructions rather than a simple transcription of visual cues, the kind of scientific representation that utilises what Ihde terms 'second sight' because 'it is a translation into the visible of phenomena that lie beyond literal vision'. Let the details a translation into the visible of phenomena that lie beyond literal vision'.

In tandem with other brain imaging technologies, from the EEG and MEG to PET scans, fMRI gives a sense of seeing 'inside' the brain. This has an inevitably disruptive effect on the black box model since, as Waldby puts it: 'The humanist commitment to the unknowable interior is necessarily destabilized by any attempt to treat the interior as itself surface.' New

⁸ Butler (2005), p 41.

⁹ Butler (2005), p 42.

See Waldby (2000). This, in turn, takes place against a broader theme of what Ihde calls a scientific culture of 'visualism': Ihde (2002), Ch 3.

Rees (2011), p 19.

Ihde (2002), p 47.

¹³ Waldby (2000), p 159.

visualising and interventionist technologies that seem to 'open up' the brain are continually being reported. However, while visual depictions of brain anatomy are powerful enough, the visual depiction of 'function' is what sets fMRI apart. Function, in the brain, stands for dreams, memories, decision-making, secrets and emotions, the content of our most private selves. Brain scanning of function allows scientists to assert that there is no inherently unknowable interior space: 'non-invasive imaging technologies ... have provided overwhelming evidence that even our most "private" thoughts, decisions and emotions are preceded by the activation of defined networks of neurons'. In other words, the 'container' function of the brain is no longer a barrier against incursion – or at least incursion in the form of the technologically competent 'expert'.

With its promise of revealing the internal contents of our minds via the 'second sight' of the expert, the fMRI has captured the attention of scientists and the general public alike, and in recent years there has been a steady stream of media reports and popular articles 'translating' scanning research into private areas of public interest: health, relationships, sexuality, gender and child rearing, to name a few. 16 Contemporary research into the brain is often described as an 'unlocking': the black box of our brain is being opened and examined. 17 For instance, in one brain-scanning experiment, scientists showed that they could tell what the scanned individual was going to decide well before the subject was aware that they had made up their mind. In this experiment, while the research subject was lying in the MRI machine, weighing up his or her options (whether to press a button with a right or left finger), neuronal activity showed that the choice was already made, and the scientists could 'read' and record this decision up to ten seconds before the subject had consciously decided. 18 This leaves the scientist seemingly in

For example, as I was writing this article a new way of processing MRI data was reported that maps myelin, the protective coating of neurons: Glasser and Van Essen (2011). Previously, such maps could only be made with dissection, not on a living brain. Another technology, that literally shines light into the brain, reported on recently in *Wired* magazine as one of the 'Seven creepy technologies that could teach us so much (if they weren't so wrong)' is optogenetics, currently being carried out on mice, which switches on and off individual neurons by targeting them directly with light (after genetically modifying them to be light sensitive). Human application is clearly problematic – or 'creepy' to use *Wired*'s term – but researchers have nevertheless claimed insights into human disorders such as autism using this method. 'Seven Creepy Technologies That Could Teach Us So Much (If They Weren't So Wrong)', *Wired*, 15 July 2011.

¹⁵ Singer (2011), p 42.

See, for example, 'Scientists Discover True Love', The Sunday Times (UK), 4 January 2009; 'Rejection Really Hurts, Brain Scans Show', National Geographic News, 28 March 2011; 'The Brain Scans That Prove Couples Share a "Sixth Sense", The Daily Mail (UK), 27 September 2010; 'Secrets of the Female Orgasm Uncovered', Sydney Morning Herald, 9 November 2010. For an academic analysis of neuroscience research in the popular domain, see Racine (2010), Ch 5.

See, for example, Ramachandran (2011).

Singer (2011), p 43.

possession of what on the black box model would have been an 'unknowable', subconscious component of thought, disrupting any sense of privacy from the outside world. Neuroscientist Michael Gazziniga writes that '[n]euroscience also tells us that by the time any of us consciously experience something, the brain has already done its work ... This raises the question, are we out of the loop?'19

The newly celebrated plasticity of the brain works in tandem with function scanning to intensify the idea that the brain is not a closed box. While plasticity research is not dependent on fMRI for its insight into the brain – observational studies and invasive animal experimentation are among other research methods that have played key roles – scanning certainly demonstrates the existence of plastic change. More importantly, plasticity reveals a brain in constant modification according to the external environment: 'perpetually altered by every encounter, every interaction'.²⁰ This idea is discussed further below, but for now the crucial point is that plasticity further undermines the 'black box' model of the brain by showing it to be continuously open, interactive and changing. Furthermore, while opening up the brain is a precursor to therapeutic intervention, 'rendering the human brain plastic has made it more amenable to therapy'.²¹

The Control Model

The idea, courtesy of brain imaging technologies, of brains as readable and changeable has so far offered the public domain a positive and satisfying experience of control. The prevalence and popularity of books on brain management demonstrate this, as does the ubiquity of popular magazine and newspaper articles representing the brain as able to be rejuvenated, with sufficient attention to 'exercise' – or what is now termed 'neurobics'.²² These self-improvement texts tap into the deep Western anxiety around ageing, and expand the promise that by exercising the body (along with a host of other purportedly age-defying interventions) physical decline can be staved off. While the brain was viewed as static and slowly declining, it posed a threat to the fantasy of endlessly prolonged vitality. With visibility and the possibility of change, the brain becomes another organ to be exercised 'as

⁹ Gazzaniga (2005), p 89.

²⁰ Doidge (2010), p 209.

Rubin (2009), p 421. She adds: 'Undoubtedly, structural plasticity adds a further therapeutic dimension to the existing neuroscientific catalogue, implying that not only the function of synaptic connections might be modulated by the administration of proper treatments, but also their very existence might be amenable to therapeutic measures.'

A few examples of such titles, currently being advertised at a local bookstore, are: R Restak and S Kim, The Playful Brain: The Surprising Science of How Puzzles Improve Your Mind; Michael J Valenzuela, Maintain Your Brain: What You Can Do to Improve Your Brain's Health and Avoid Dementia; Daniel G Amen Change Your Brain, Change Your Body; and John Medina, Brain Rules:12 Principles for Surviving and Thriving at Work, Home and School.

though it were a muscle',23 with crosswords, Nintendo games, Sudoku, omega 3 supplements and daily moderate exercise – or, more intensively, with brain devices and neurofeedback.24

While this quite dramatic and intense sense of control over our brains imparts the pleasurable fantasy that we will not be helplessly subjected to natural forces of age and decline, and so perhaps will be able to cheat or postpone death, it also has a more subtle and wearying effect. This is in the maintenance of what Rose calls the 'neurochemical self', a self whose internal life – thoughts, desires, feelings, decisions – is mapped on the body, and specifically the brain.²⁵ The neurochemical self is one that, in constant interaction with health and other experts, is always attendant to bodily risk and to the conscientious management and mitigation of risk. Therapeutic intervention is reshaped by the neurochemical self, which in assessing and managing risks, self-regulates. In this, Rose is presenting a version of Foucauldian technologies of the self adapted to contemporary biosocial practices.²⁶ Neuroscience and its visual techniques have become some of the practices by which we form our selves.

The anxious self-regulation associated with openness and visibility is encouraged by the way that fMRI, even as it opens the interior of the brain for study, permits a continuation of the 'black box' model in one respect: it presents the brain in isolation from the body. The image of the brain on the screen, lighting up on its own, directs focus to the organ itself, and truncates the view of any other part of the body that may be involved in its functioning. Even the title of the popular book *The Brain That Changes Itself* reflects the persistent idea that the brain is an individual unit – an agent, even, of its own destiny – shaping itself, regulating itself. Yet an arguably more accurate way to represent openness and plasticity would be the more reactive: 'The Brain That is Changed by Others', or even better: 'The Brain That is Embedded in Otherness'. How we might 'see' such a brain is explored below.

The Open Brain

The Technological Moment

The ability to see brain functioning, and the disruption to the black box model, allow a more radical questioning of how we think of the brain. Indeed, at this point of using fMRI to 'see' thought processes, we are at a moment of heightened transparency that occurs when new technologies create a schism in an accepted pattern of thought, and allow for the perceived natural order of things to be overturned. This moment of visibility

²³ Doidge (2010), p 36.

See Brenninkmeijer (2010).

²⁵ Rose (2007), p 188.

²⁶ See Martin et al (1988).

²⁷ Doidge (2010).

as a technology emerges takes place in what Waldby calls 'the lag between an innovation and its domestication'. ²⁸ In this moment, technologies can provide, in Franklin's term, a 'defamiliarizing lens', ²⁹ allowing us to see the world anew.

Neuroscientists share a high degree of consensus about the basic nature of the brain and the mind/self, seeing the mind as biologically based. In its strongest form this biological view is 'a fully fledged reductionist collapse which sees mind as merely the epiphenomenological product of brain'. Science writer and neurobiologist Lone Frank, who refers to herself as 'a bag of neurons', expresses the reductionist turn more floridly, calling this anchoring of the formerly incorporeal into exchanges of chemicals and electrical signals a 'neurorevolution'. 'Religion is gone,' she writes, 'moral choice ... is ascribed to automatic processes that are planted in us all by a blind, value-neutral evolution.' ³²

However, this consensus of belief does not exist outside of the neurosciences, where ideas about brains, consciousness and an array of associated concepts are contested. Martin writes that although a brain-based account of consciousness is almost universally accepted in the neurosciences, explanations of brains – what they consist of and what they do – are highly contentious in other academic disciplines and the public domain: 'Instead of a certain take-over by a newly dominant paradigm, we are witnessing an open moment whose outcome is far from clear.'³³ The 'technological moment' of visibility is here for brains, a chance to consider which elements of a brain-based account of identity should be integrated into attendant laws and norms regulating bodies.

Law and the Technological Moment

What might this particular 'technological moment' mean for law? Much has been written of the possible challenges to law of current shifts in thinking about the brain – for example, the challenge to free will and criminal responsibility posed by the ability to provide a biological basis for decision-making and choice.³⁴ Some commentators believe that because of brain scanning, neuroscience will effectively take over some areas of law.³⁵

²⁸ Waldby (2000), p 20.

²⁹ Franklin (1998), p 103.

³⁰ Rose (2004), p 5.

Natasha Mitchell interview with Lone Frank, 'All in the Mind', ABC Radio National, 29 May 2010, www.abc.net.au/rn/allinthemind/stories/2010/2909156.htm.

³² Frank (2009), p 13.

³³ Martin (2010), p 367.

See, for example, Aharoni et al (2008).

^{&#}x27;As with so many issues where modern scientific thinking confronts everyday realities, the people in the jury box are not rushing to embrace [question of free will]. Yet it is my contention that even those tough jurors will have no choice, because some day the issue will dominate the entire legal system.' Gazzaniga (2005), p 88.

However, both Martin and Rose argue that law will be particularly impervious to the dominant scientific consensus on brain-based identity. on the much-discussed potential of brain-scanning technologies to undermine the legal concept of criminal responsibility, Rose points out that it is 'prevailing notions of moral and political order' that feed legal fictions of free will, autonomy and personal responsibility, not science.³⁶ Former Lord Justice Sedley describes the courtroom experience of being presented with scientific evidence that shifts and even reverses over time, and where scientific experts on each side of a case present conflicting views. He writes that 'in the absence of a confirmed or at least a compelling aetiology of human conduct ... the law ... goes on to construct its own paradigms of human responsibility from its experience of two chief things: the ambit of human frailty and the social consequences of irresponsibility'. 37 Furthermore, Rose argues that the legal trend is towards greater culpability and individual responsibility. Functional brain imaging evidence may indeed influence against mitigation: 'For if antisocial conduct is indelibly inscribed in the body of the offender, reform appears more difficult, and mitigation of punishment inappropriate.'38

If law is indeed more impervious to the dominant scientific take on brains, will these major shifts in thinking about the brain have any effect? Rose suggests that a control model will win out and that an intensified biological regulation/self-regulation is the most likely outcome. This will not mean that individuals will have reduced moral responsibility under law because of biological factors that might make unlawful actions seem predetermined, but that screening will become a ubiquitous way of identifying and avoiding the risk of unwanted patterns of behaviour. In fact, Rose predicts that in place of the Foucauldian 'discipline and punish', a regulatory regime he terms 'screen and intervene' – a way of using fMRI to predict and therapeutically mitigate against the possibility of unlawful (or otherwise undesirable) behaviour – will emerge.³⁹

The Open Brain as Embedded and Embodied

I argue instead for a way of seeing the new brain that might avoid both the limitations of the black box model, with its atomistic sense of self, and the control model represented by Rose's screened and regulated neurochemical subjects. An alternative to these, implicit in the scientific findings of fMRI scanning and plasticity but not articulated in mainstream representations, is an open brain, structured through interaction with the environment and others. Without any clear border, the brain is more accurately acknowledged

³⁶ Rose (2007), p 235.

Sedley (2004), pp 128-29. Sedley also states: 'We do not know what we shall do if aggression turns out one day to be biologically determined, or if pharmacological or genetic intervention becomes able to produce results which fines or treatments do not achieve.'

³⁸ Rose (2010), p 84.

³⁹ Rose (2010).

as both embodied and embedded – embodied because it is inseparable from its functioning within the body, and embedded in its environment and in other people.

Clearly, the brain is embodied within a nervous system, but it is also inseparable from the whole complex of biological systems that make up the human body. Wilson writes that 'there is no such thing as a brain, there is always a brain and another system'. Wilson's work on the gut shows that the work of anti-depressants – commonly thought as directly impacting seratonin levels in the brain, and easily conceptualised as a therapeutic neurological intervention – is in fact imbricated in a complex of bodily systems, including 'enzymes in the liver, conditions in the gut lumen, and the psychocultural milieu governing diet'. The most expansive understanding of the brain sees it as embedded in a set of bodily relations, from which it cannot meaningfully be separated.

As well as being embodied in a unique and complex set of interlocked biological systems, the brain and associated body systems are embedded in a physical and social context.⁴² As demonstrated by the plasticity of its structure, the brain is in a constant process of change – far from static, it is 'a relational organ'.⁴³ Wilson makes this point when she describes the chemistry of the brain as embedded in 'the psychocultural milieu governing diet', because the types of foods consumed within a specific culture will have differing proportions of, for example, carbohydrates or dairy foods, which will determine the level of body products such as insulin in the blood, which will in turn impact the uptake of amino acids (a building block of seratonin) to the brain via the gut. Another example lies in the way the brain intermingles with its current environment to record information intake, matching environmental cues with memory retrieval:

[The brain] colors the terms of the Versailles Treaty with the wasted fluorescent glow of the dorm study room, say; or the elements of the Marshall Plan with the jade-curtain shade of the willow tree in the backyard.⁴⁴

As well as being fundamentally integrated into the body and environment, the brain is 'perpetually altered by every encounter, every interaction'. In every conversation, through every slight shift in

Wilson (2006), paraphrasing psychoanalyst Winnicott, p 130.

Wilson (2006), p 129, writes: 'Just how isolated and autocratic is the brain? ... Notions of the brain as an autonomous, self-contained organ are common enough in both the scientific and popular imaginary ... [As we follow the data on the brain-blood barrier we find that] ... the brain is always, necessarily implicated in relations with other organs and other extra-bodily systems; the blood-brain barrier is one particularly intensive site for such xenobiotic transmissions.'

^{42 &#}x27;Our brains and minds are not only embodied but embedded in the social and physical environment with which we engage.' Glannon (2009), p 325.

⁴³ Glannon (2009), p 328.

^{&#}x27;Forget What You Know About Good Study Habits', New York Times, 6 September 2010.

⁴⁵ Doidge (2010), p 209.

environment, every tiny nuance of touch, smell or taste, the brain is radically open, constantly responding and restructuring.

Theorists such as Glannon refer to this interaction of the brain with body and environment as the 'distributed mind', meaning that consciousness cannot be reduced to the brain, but is distributed between brain, body and environment.⁴⁶ But the brain can no longer be confined to the organ itself. Where, after all, are the meaningful boundaries of a brain that is intermingled to such a radical degree with body systems, environment and other people?

The open brain model is closer to the work of Haraway, who presents the body and its biological systems as inevitably intertwined and interdependent, teeming with life of all sorts and inseparable from technology. Haraway has written extensively about the essential porosity of the human body, and in her most recent work she describes the body as dependent on other species for existence, saying that: 'To be one is always to become with many.'⁴⁷ If we are radically open – shaping and being shaped by each other through interaction – then our brains are also 'becoming with' each other, as well as with other species and our environment. 'Becoming with' captures the two elements of the brain whose significance is being underplayed in current writing on neuroscience and which are crucial to an open brain approach: 'becoming' captures the lack of stasis over time, the brain in constant change, and 'with' captures the central role of relationships in the structuring and restructuring of the brain.

Law, Disability and the Open Brain

What would the 'open brain' model mean for law if the 'black box' model is a foundational characteristic of the liberal legal subject, and the control model, represented by Rose's negative prediction of a 'screen and intervene' future, bypasses law for neurochemical intervention? Surprisingly, since it is more commonly in harmony with the controlling rather than the radical aspects of emerging technologies, law has gone some way towards acknowledging the embeddedness of identity in an area that deals with the diversity of brains as well as other body types: disability discrimination laws.

The Deficit and Social Models of Disability

Traditional definitions of disability have relied on what is termed the 'deficit' or 'medical' model of disability. A reductionist model (like brain-based views of consciousness), the deficit model locates disability solely in the body of the person with the impairment. On this view, if the impairment

⁴⁶ Glannon (2009), p 329.

⁴⁷ Haraway (2008), p 4.

could only be removed, cured or eradicated, there would be no disability, no ground for discrimination and no problem for law to redress.⁴⁸

Discrimination laws have largely followed what could be termed a 'deficit' model of identity. They locate the protected attribute – race or sex, for example – in the bodies of those who are already stigmatised for those attributes. Thus it is the body, already hypervisible as raced or sexed, that is on display and that then becomes further associated with vulnerability and disadvantage:

It is the stigmatized body that is made to 'wear' embodiment: the normalized 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 acknowledgment reinscribes the relative privilege and disadvantage of the parties.⁴⁹

In other words, a deficit model in discrimination law leaves privilege intact: what it means to have a 'normal' body is not interrogated, since normalised bodies are not identified as raced, sexed or disabled. In fact, this model contributes to the normalisation of certain bodies, in part through the cocreation of a category of 'disability'. The deficit model is a way of protecting particular disadvantaged groups of people, but clearly carries with it a heavy burden.

Compared with the deficit model, the social model is a welcome shift of attention. The social model of disability locates disability not in the body of the person with the impairment, but in the society that sets up the conditions for attendant suffering and exclusion. 50 It is this suffering and exclusion that, on the social model, is the disability. Buildings without ramps, taxis that do not accommodate wheelchairs, colleagues who cannot sign, documents in formats that cannot be electronically read to the sight-impaired, working hours that do not accommodate chronic illness - these create disability, since without them, the argument goes, impairment would not result in a constrained public life. On the social model, disability is 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have ... impairments and thus excludes them from the mainstream of social activities'.51 In its strongest form, the social model holds that disability is 'solely the result of created social exclusion', and in its minimal form it holds society responsible for accommodating people with impairments so that they are effectively not disabled.⁵² Social disability activists acknowledge impairment in the body,

For a discussion of some of the theoretical debates around the construction of disability, see Karpin and Savell (forthcoming 2012), Ch 1.

⁴⁹ O'Connell, 2009, p 144.

⁵⁰ See Shakespeare (2006); Thomas and Corker (2002); Thomas (2007), Ch 3.

Statement by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976, cited in Thomas (2007), p 52.

⁵² Baker (2006), p 177.

but the distinction between biological impairment and social disability, and a focus on the latter, are 'at the heart of the social model'.53

The social model has influenced disability politics and studies, but in its more extreme forms it has justifiably been criticised, often by feminist scholars, for its various theoretical gaps – such as the tendency to ignore embodied experience⁵⁴ and to leave 'impairment' unexamined, as if impairment is not also socially constructed.⁵⁵ It has also been criticised for the simplistic division between 'impairment' and 'disability' – Shakespeare asks whether, for example, it is possible to say whether a woman with multiple sclerosis is depressed because of impairment effects or society⁵⁶ – and for its assumption that all disability can be 'removed' by social changes.⁵⁷ It is impossible to imagine a society in which all impairments are ideally accounted for, since what suits one person's situation will not suit others.⁵⁸

Shakespeare argues that the social model is 'not a theory, an idea or a concept', and that more sophisticated models are needed.⁵⁹ Yet the social model is an important antidote to the deficit model, which retains enormous force in medicine and in law,⁶⁰ and a key means of shifting the focus in discrimination law from the individual to the society and from direct to systemic discrimination, and of creating more meaningful equality laws. The social model, as discussed below, did impact the development of federal disability discrimination laws in ways that are important if not sufficient. The social element should remain a component of thinking about disability, discrimination and the brain, as an impetus to scrutinise how ability and disability are constructed. This is a theoretical *orientation*, rather than a definitive framework that directs thinking to aspects of discrimination that are often overlooked.

In terms of the competing brain-based identity models, the deficit approach evokes the control model of the brain, with its focus on biology and intervention at the level of the individual. In contrast, a social orientation towards disability resonates with the 'open' idea of the brain: it makes no sense to see disability, the body or the brain in isolation from the set of social and cultural systems in which it is embedded. A social model alone is insufficient for brain-based or disabled identity, however, since it is the interplay of the social with the biological that allows for a more nuanced approach.

⁵³ Thomas (2007), p 69.

See, for example, Wendell (1996).

⁵⁵ Davis (2006), p 237.

Shakespeare (2006).

⁵⁷ Scully (2008), p 26.

⁵⁸ Scully (2008)

⁵⁹ Shakespeare (2006), p 203.

⁶⁰ See Frazee et al (2006).

Contemporary disability theorists are building the kinds of sophisticated models that Shakespeare desires – models that reflect the layering of relations that create, sustain and give meaning to impairments over time. ⁶¹ As Thomas puts it, the body is 'simultaneously biological, material and social', ⁶² but the strength that will be given to each of these elements is clearly contextual, and which strands – if any – will exert influence over law and policy reform is yet to be seen. A promising development is the recent UN Convention on the Rights of Persons with Disabilities, which states:

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others ...⁶³

This definition acknowledges the relational and temporal aspects of identity that are key elements of the open brain model: disability (and ability) evolve over time, in relation to others and the environment in which they are situated.

Models of Identity and the Disability Discrimination Act

As discussed above, the *Disability Discrimination Act 1992* (Cth) ('the DDA'), was influenced by the social model of disability. The federal *Disability Discrimination Act* defines disability broadly. Section 4 states:

'disability', in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions;
 or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or

Frazee et al (2009), p 226.

⁶² Carol Thomas, cited in Scully (2008), p 29.

⁶³ 'Preamble', UN Convention on the Rights of Persons with Disabilities, s (e).

- may exist in the future (including because of a genetic predisposition to that disability); or
- (k) is imputed to a person.

To avoid doubt, a *disability* that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability.

This incorporates elements of the 'social model' of disability, by including disabilities that no longer exist, or may yet exist, or are imputed – in other words, disabilities that exist through relationship with others and over time. This resonates with the open brain model by reflecting the process of 'becoming with'; as with the UN Convention on the Rights of People With Disabilities, the definition acknowledges that disability may emerge over time, being projected into past and future, and that it comes to be only in relationship to another. Baker and Campbell point out that the definitional sections of the DDA 'not only invoke the fluid and temporal aspects of "embodiment"; they recognize the constructed and relational dynamics of disability as a signifier'.64

The DDA also establishes layers of responsibility for preventing discrimination against a person with a disability (or impairment). There are individual complaints mechanisms, in which a person who has been treated less favourably in a defined area of public life may seek redress from another individual or organisation. There is also legislative provision for 'action plans' to encourage organisations and service providers to actively adopt measures to address their own institutional barriers to equality.65 Finally, the DDA allows for the development of standards,66 aimed at more systemic forms of discrimination and designed as 'educative mechanisms to mould the proper attitude towards people with disabilities and their carers, and to rid society of stigma based on lack of understanding'.67 All of these measures have had some success, although they have also been criticised for not going far enough,68 but more importantly they further represent a legal approach to identity-based harms that distributes responsibility across a spectrum from the individual to the institution to the state. Basser and Jones refer to this as a 'three-dimensional approach' with the potential to genuinely 'operationalise' human rights for people with disability because it allows for involvement at all levels of society.69

The model of disability reflected in the DDA holds out promise as a model for embedded identity, since it finds that the 'identity' of being disabled resides throughout layers, from individual to social. This gives the DDA further resonance with a view of the brain that is embodied and

Baker and Campbell (2006), p 326

⁶⁵ Sections 59–65 of the Disability Discrimination Act.

⁶⁶ Section 31.

⁶⁷ Basser and Jones (2002), p 84.

See discussion, for example, of the *Purvis* case below.

⁶⁹ Basser and Jones (2002).

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embedded. However, in practice the DDA does not fulfil the promise of being a legal model for an embedded identity. This can be illustrated by a case study of disability discrimination: people with neurological disorders that manifest with anti-social behaviours. First, however, it is useful to turn to the writings of a sub-group of people with neurological conditions who see themselves as different, not deficient: neurodiversity activists.

Neurodiversity and the Open Brain

The social model of disability – and the brain – is strongly reflected in the writings of contemporary neurodiversity activists, mostly those on what is commonly called the 'high-functioning' end of the autism spectrum, but also those with Attention Deficit Disorder (ADD), Tourette's Syndrome or other neurological conditions.⁷⁰

Advances in medical science – particularly neurological and genetic sciences – are expanding the set of behaviours – from aggression to addiction – that might be categorised as disabilities. In addition, in recent years (and for contested reasons ranging from environmental causes to more rigorous diagnosis) there has been a significant increase in the prevalence of neurological conditions such as autism, Asperger's Syndrome and ADHD. The rapid increase in the numbers of people exhibiting these neurological traits, as well as a range of new categories and descriptors of neurological impairment, led one journalist to comment on the 'shrinking subset of [the] neurologically normal'.

The increase in size and scope of the neurologically atypical population has been accompanied by a social movement that calls for acknowledgment of and respect for neurodiversity. Websites such as 'Aspergian Pride' and 'neurodiversity.com' promote the belief that neurological difference should be celebrated rather than cured, and that cognitive divergence is part of the rich variation of humankind. The 'problem', neurodiversity activists argue, lies squarely with the 'neurotypical' society that cannot accept different ways of thinking or behaving. Some even claim that the characteristics of their supposed impairment, far from being disabling, are ideally adapted for contemporary life. Singer, for example, argues that autistics are best able to function in a computer age:

Consider how computers force us to deal with an overwhelming onslaught of pure information, minus emotional cues and feedback,

The term 'autism spectrum' is itself problematic: journalist Andrew Soloman (2008) refers to it as a 'three-dimensional universe of behaviours as challenging to define as the notion of human personality itself'. It is important to note here that there are many on the spectrum, or with other neurological impairments, who disagree with neuroactivists, who do express a desire to be 'cured' of autism or whose cognitive or communication skills are too impaired to express a view. The politics of autism identity are highly contentious, but this article focuses on those in the highly vocal and articulate pro-neurodiversity subgroup because of the particular challenge they offer to law in its approach to disability.

⁷¹ 'Neurodiversity Forever: The Disability Movement Turns to Brains', *New York Times*, 9 May 2004.

how they replace the complexities of intuitive decision-making with simplified, rule-based machine logic. When these simplistic systems cannot respond fluidly enough to complex realities, even NTs [neurotypicals] can be reduced to the frustrated head-banging rage which is the old hallmark of autism. If every age has its 'disease metaphor', then is autism the metaphoric 'disease' for the era of the Internet?⁷²

Neurodioversity activists present an intensified version of the 'social model', making society not only responsible for the barriers that make their neurological makeup into a disability, and contesting that there is any impairment at all outside of the social construction of it – but further, locating disability in the people, the 'neurotypicals', who generally get to enjoy the privilege of being 'normal'.

Neurodiversity activists do not, however, have a model of identity that is particularly complex or embedded. Ortega has pointed out the reductionism of much of the language: neurodiversity activists do not use the phrase 'people with autism' because, they say, they *are* autistics. They describe autism as being 'differently wired' and locate it clearly in the brain. In fact, they often describe themselves *as* their brains. Nevertheless, neurodiversity poses a challenge to law because it offers a way of seeing the 'disabled' brain that is in keeping with other activist movements that have driven legal protection for other identity-based groups by framing stigmatised difference as positive diversity.

So how does law deal with the neurologically diverse? Since the DDA, more than other anti-discrimination laws, makes some effort to embed identity in a social context, we might expect that it is able to respond effectively to people discriminated against for these neurological disorders. Sadly, that is not the case. Discrimination law still struggles to deal with the neurologically different. For example, in the *Purvis* case, the High Court of Australia interpreted disability discrimination laws narrowly to deny legal protection to a school student displaying aggression and atypical behaviour. A spate of recent cases in the same field – disability claims against schools by students with autism, learning or behavioural issues – shows that the issues of exclusion or unfavourable treatment remain, but after *Purvis* the possibility of successfully bringing a direct discrimination case on the basis of behavioural issues is remote. The property of the possibility of successfully bringing a direct discrimination case on the basis of behavioural issues is remote.

⁷² Singer (1999), p 66.

⁷³ Ortega (2009).

Purvis v New South Wales (2003) 202 ALR 133. This case has been criticised by many commentators: for one example, see Campbell (2005).

See, for example, Alex Walker v State of Victoria [2011] FCA 258; Abela v State of Victoria [2011] FMCA 331 (2 May 2011) (still proceeding); Ives & Ors v Kilvington Grammar Ltd & Anor [2008] FMCA 1414 (30 October 2008) (settled out of court); Mason & Anor v Methodist Ladies College [2009] FMCA 570 (17 June 2009) (settled out of court); State of Victoria v Turner [2009] VSC 66 (4 March 2009) (appeal of successful

So why does the more complex model of disability allowed for in the DDA appear to be having little impact on individual cases of neurodiscrimination? Unfortunately, while the DDA acknowledges social responsibility for disability, each of the limbs – individual, institutional and community – operates separately, so that while a school may be subject to education standards or even have an action plan, an individual complaint will still be determined by the traditional deficit definition of disability, rather than the more radical idea of disability as located within the school and wider society. In the recent case of *Walker*, involving a child on the autism spectrum who was excluded from school on various occasions, it was clear that for students with atypical and difficult behaviours, the legal and social tendency is to view them as troublesome individuals without a secure place in public life. ⁷⁶ In the workplace, too, the effect of disability discrimination laws in practice is individualized rather than social:

From the perspective of the person with ADHD, attention focuses on their 'not normal' behaviour, rather than on the excessively rigid 'normality' of the workplace. The law's attempts to ameliorate this rigidity, through provisions which recognize indirect discrimination and which require adjustments to be made, do not alter the threshold obstacle for a person with ADHD who has to characterize their cognitive function as a disability and take responsibility for challenging the appropriateness of workplace arrangements.⁷⁷

While the DDA has incorporated elements of an embedded identity, it is important to remember that discrimination law is embedded too – within a legal culture shaped around an understanding of identity as individual and autonomous, the self-contained boxes described earlier in this article. For those outside the neurological 'norm', law still approaches what is atypical about their brains and corresponding behaviour as the 'problem' to be addressed. A deficit and control model has trumped the more sophisticated social and open models in the application of these laws. Again, the underlying sense is that if only the brains of those with autism could be 'fixed', the problem of discrimination would disappear.

And there are significant attempts being made to cure conditions that are, or are suspected of being, neurologically based – particularly autism. Recent media stories have reported on a scan that is claimed to diagnose an autistic individual within fifteen minutes. 9 But when one part of the brain is

indirect discrimination case). For the impact of *Purvis* on potential discrimination claims by employees with ADD, see Arnold et al (2010).

Walker v State of Victoria [2011] FCA 258.

⁷⁷ Arnold et al (2010), p 375.

The powerful United States-based research group Autism Speaks (www.autismspeaks.org) is one example of the significant effort and funds being put into autism research.

Alok Jha (2010) 'Autism Can Be Diagnosed With Brain Scan – Study', *The Guardian*, 10 August 2010. A response criticising the research conclusions was published shortly after: Carl Heneghan (2010) 'Why Autism Can't Be Diagnosed with Brain Scans', *The*

identified as functioning differently to 'normal' brains in autistic research subjects, what does this mean? These scans may be identifying some kind of atypical brain feature, but whether it is negatively atypical is a much harder question — a social question. Research projects such as these already presume a brain in need of therapeutic intervention.

With the prompting of neurodiversity commentators, this raises the question of what is lost if neurological diversity can be screened for possible intervention. The neurodiversity community would no doubt argue that a 'screen and intervene' approach, if successful, would be an eradication of a positive variation in human neurology, similar to the way some sections of the deaf community view attempts to medically eradicate deafness. Viewing the autistic brain on a reductionist or individualistic model neglects the possibility of what a differently ordered brain might have to offer. Neuroscientist Antonio Damasio has commented that connecting autistic traits to brain functioning 'is going to be a rather relentless process as there are more and more discoveries of people that have something that could be called a defect and yet have immense talents in one way or another'.80

Conclusion

There are at least two contenders for a brain-based identity to replace the 'black box' of the brain: a reductionist, control model, of Rose's 'screen and intervene', the regulated and self-regulated neurochemical self; and an – admittedly quieter – 'open model' of a self embedded in otherness and changing over time.

The neurologically atypical brain can be viewed differently via the open brain model. The open brain model gives an orientation towards the body and environment in which the brain is embedded. For example, in a 'control' society of the sort Rose describes, where self-scrutiny and self-regulation are the social norm, atypical behaviours are more unsettling and unacceptable. Those who are advocating a neurodiversity approach are not good neurochemical citizens, self-monitoring and self-controlling, according to a socio-medical ideal. Through their failed citizenship, they challenge the idea of self-regulation, and instead pose the question of what a society would look like that was more tolerant of a range of behaviours and neurological styles. Ironically, given autism's association with isolation and anti-social behaviour, they refuse to accept individualist readings of disabled identity, arguing that their construction as 'disabled' is dependent on a particular social reading of their brains.

The future that Rose foresees, where identity is pre-emptively controlled through neurotechnologies, bypasses law, with all its flawed but important attempts to protect people from identity-based harm. The open

Guardian, 12 August 2010. Another brain scanning research project is the Infant Brain Imaging Study (IBIS), which is scanning infants with an older sibling on the autism spectrum: www.ibis-network.org.

⁸⁰ Cited in 'Neurodiversity Forever: The Disability Movement Turns to Brains', New York Times, 9 May 2004.

model of the brain is not one that provides an essentialist identity as a basis for law: its very point is that identity is never static or complete. What it does allow for is the possibility of an ongoing orientation towards how identity is being constructed, and attention to the various layers that play in its construction.

The control model also takes us away from the idea of 'unknowability' as a source of ethics, by asserting that even the most seemingly private aspect of identity is in fact knowable and potentially subject to regulation, without allowing for any alternative. In contrast, the open brain approach reveals that once the inherent 'unknowability' of the self is removed as an element in the construction of identity, another kind of relation to the Other emerges. Neuroimaging and plasticity reveal the self-as-otherness, the self constitutive of and embedded in the Other, even as the self is correspondingly remade. It is no longer the 'stranger within' that is the source of the ethical relation, but the 'otherness in each other' that orients the individual to how the other fares. Emerging brain-based technologies have showed us that we are not sets of black boxes, closed and unreadable, but nor are we knowable in any uncomplicated sense – we are something equally mysterious and deep, even if that depth is located, in part, outside of ourselves.

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