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Disabling Able

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(In memory of Chris Newell)

With its title 'able', this issue called for articles and essays which explore ability from a disability perspective, rather than disability from an able-ist perspective. One take on the title 'able', is that it invites a fresh perspective on disability, with a focus on abilities and productivities (defined differently, in non-able-ist terms), rather than lack and aberrance. This affirmation of abilities is characteristic of many of the articles and essays in this issue, particularly in the narrative accounts of lived experience. Another take on 'able' evident in these articles is the critique of able-ist assumptions and discourses.

Some writers, such as Campbell, Goggin and Wolbring, overtly address the value of insights offered through disability to deconstruct the 'able-ist' perspectives which dominate and limit our social worlds, even within disability studies. Campbell provides an overview of scholarship on disablism and able-ism: 'Disablism' works as "a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities". While Campbell acknowledges the importance of disability studies with its various critiques of the practices and production of disablism, "specifically ... examining those attitudes and barriers that contribute to the subordination of people with disabilities in liberal society", she also identifies an 'able-ist project' within disability studies, which can serve to reinscribe the able-ist perspective and assumptions. Campbell argues: "the challenge then is to reverse, to invert this traditional approach, to shift our gaze and concentrate on what the study of disability tells us about the production, operation and maintenance of ableism."

Goggin also calls for this inverted approach, with scrutiny of the under-examined category 'able':

If we think of the impact and significance of "whiteness", as a way to open up space for how to critically think about and change concepts of race; or of "masculinity" as a project for thinking about gender and sexuality — we can see that this interrogation of the unmarked category of "able" and "ability" is much needed.

Goggin notes that while disability has been subject to critique and examination (like the all too conspicuous and scrutinised disabled bodies), there has been surprisingly little critique of ability: "nor have we witnessed a thoroughgoing recognition of unmarked, yet powerful operations of ability in our lives and thought". Wolbring also contends that "there is a pressing need for society to deal with ableism in all of its forms and its consequences". Through his discussion of categories of 'able' and 'ableism', he identifies a dominant discourse around 'species-typical' versus 'sub-species-typical, defined from the dominant 'able-ist' perspective.

This discourse has a long history and is linked to the discourse around health, disease and medicine. This is ... a model that classifies disabled people as having an intrinsic defect, an impairment that leads to 'subnormal' functioning.

He insists on the importance of work within Disability Studies which questions that medical model and explores the issue of 'who defines whom' as sub-species typical.

Many of the articles published here recognise the interdependence of such categories of 'abled' and 'disabled', drawing attention to the work they perform – usually naturalised and invisible – in producing 'common sense' understandings of human value and performance. The able-ist perspective produces disability in terms of lack and deviance from the human norm (which Wolbring calls 'species typical'). This able-ist production of disability – with its sense of lack and revulsion for the aberrant body/mind – is a powerful undercurrent informing our understanding of human agency. It underpins legitimising discourses which define humanity, particularly modernist discourses of medicine and technology which address the 'improvement' of human lives and promise to eradicate disability. It is also crucial to the meaning of so many media narratives, since such narratives, whether in

news, documentary or film/tv drama, are predominantly about dilemmas of human agency, of people's ability or failure to act, to overcome setbacks and limitations.

The notion of agency – which drives or impedes the narrative and its resolution – is just as prevalent in media narratives which include people with disability, even those narratives which celebrate their outstanding achievements (*in spite of* disability). The disability becomes the impediment that must be overcome or be transcended. This more general pattern is represented in emblematic form in many Hollywood action narratives: sometimes the 'villain' who impedes the hero's path is 'disabled', or the hero must overcome some disability within themselves (often figured as a temporary disability – such as Superman's disablement with exposure to kryptonite). While such media stories offer extremes of the ability/disability paradigm, the categories inform our wider debates and understandings of human performance and value.

Human agency and the improvement or enablement of this agency - configured in conventional 'able-ist' terms - is key to narratives in medical science, technology and innovation, education, as well as in literature and culture, and media narratives which define and interact with our understandings of human activities and performance. Several articles in this issue examine the relationship between technology and innovation, and the able-ist project of modernity and its positioning of people with disability. Goggin addresses the relationship between technology, innovation and disability, calling for a reversal of mainstream logic which sees technology as something which ameliorates disability and improves the lives of people with disability. He points to the work of writers who demonstrate the vital role of people with disability as users of technology, to inform design in the innovation process, and improve the lives of all users of technology. In this context the 'disability perspective' helps break through the limitations of the able-ist perspective. In their article "iTunes Is Pretty (Useless) When You're Blind", Kate Ellis and Mike Kent critically examine the promise of digital technology "to open up the world to people with disabilities", showing the limitations of iPods and iTunes for many people with disabilities (in particular the difficulties for users of screen readers and Braille tablets). They focus on the way that technologies and innovations designed to improve access for people with disabilities "actually enhance access for all users". They draw on the example of the Lectopia lecture recording and distribution system which has enhanced the educational outcomes for all students where it has been adopted. This resonates with Goggin's piece on technology and innovation, and the benefits of converging the perspective of the disabled user, with the 'user' as considered in technology design.

In her article on photographer William Yang's photographic portraits of his friend Allen dying of AIDS, Catalina Florescu addresses the history of medicine and its role in perpetuating 'able-ist' evaluations of disability.

In the nineteenth century, how much was medicine responsible for defining ugly as ill, deformed, and getting old, versus beautiful as healthy, and then, for the sake of the community's health, firmly promoting these ideas? Furthermore, with the rise of photographic art, medicine was able to manipulate and control these ideas even more efficiently.

She quotes Deborah Lupton, "the new technology of photography that developed from the mid-nineteenth century became a valuable strategy in the documentation of patterns of disease and illness, and the construction of the sites of dirtiness and contagion". This emphasis on the historical role of technology in managing and defining, and potentially redefining, understandings of ability and disability, is similar to the scrutiny of technologies that occurs throughout other articles and essays in this issue, including those essays by McDonald, Wain and Place, which address the lived experience of disability.

Human agency is also a central theme in cultural and media studies: the modern impulse to bring about social change through critique, depends on a belief in human agency and in the ability to generate change and address social inequalities. The recognition of the role of culture, language and representation, in the contested domain of (unequal) social relations, is vital to critical practice within cultural and media studies. Given this belief in human agency, the assumption that human subjects are *able* to change the social order, it is vital for practitioners of cultural and media studies, to question the nature of those assumptions, aware that human agency is so often defined in 'able-ist' terms. As such the writings in this issue bring a valuable perspective to cultural and media studies more generally, through their critique of the able-ist assumptions that underpin conventional understandings of human agency.

Several articles in this issue examine media representations, some drawing attention to those that produce different perspectives on ability and disability. Much has been written about the power of filmic, theatrical and literary representation of disability to engage with, reflect, influence and challenge dominant (able-ist) cultural and social attitudes and narratives (Garland-Thomson, Darke, Shakespeare). Bruno Starrs' piece on Dance Me to My Song (1997) reveals that while that film is listed in Rolf de Heer's oeuvre, its primary author is Heather Rose Slattery, a woman with cerebral palsy who wrote, co-directed and played Julie, the lead character. Starrs asserts that in the film Julie is not held up as an object of pity, rather is a fully embodied character, thus defying the "normality drama" (Darke) of disability which aims to "reinforce the able-bodied audience's self image of normality and the notion of the disabled as the inferior Other". In his article "Disability, Heroism and Australian National Identity", Martin Mantle analyses Chris Lilley's 2005 television mocumentary We Can be Heroes: Finding the Australian of the Year. Mantle claims that while disabled characters have been included in Australian national identity narratives, it is questionable whether they have been identified as contributing significantly to "what it means to be Australian". Lilley's satiric multiple portrayals of disabled and nondisabled characters challenge the assumptions that are made about what kinds of bodies qualify for inclusion in the "development and maintenance of a national character". The 'ableist' view of disability as impairment, rendering people passive burdens on society awaiting a 'cure', is strongly challenged in the field of disability performance art. Bree Hadley mobilises Rosemarie Garland-Thomson's comments about the 'extraordinary' body of the 'freak' and the "stare-and-tell ritual" (337) deployed by disabled performers to examine the ways in which they "negotiate the complexities of the terrain". Hadley considers the theatrical performance of Mat Fraser as Sealo the Sealboy (based on the 1940's freakshow entertainer Stanley Berent), arguing that Fraser's stage strategies deliberately confront an audience, especially a 'politically correct' one, with its own ambiguities about and fascination with disabled bodies.

A number of the articles in this issue draw directly on the experience and the socially shaped understandings of disability in the 'everyday lives' that Campbell and others speak of. Nicole Matthews writes about her charity-funded project, In the Picture which aimed to "generate exemplary inclusive" storylines and illustrations of disabled children in books for young readers by "drawing on the experience of disabled people and families of disabled children". Matthews' article focuses on the ways in which the label 'disabled' is mobilised in an analysis of the variety of responses she received to her project from both disabled and non-disabled stakeholders. She observes with some irony that the pity and charity view of disability is still socially paramount, and one that is often flexed to attract much needed funding for projects such as hers. Donna Mc Donald's piece "Shattering the Hearing Wall" reveals that one of her aims in writing a series of memoirs about being a 'deaf woman' is to produce something that rises above the "stock symbolic scripts", challenging their tendency to ascribe a singularity of identity to disabled people. Fiona Place candidly records her experiences of being the mother of a child with Down syndrome facing and transcending the "disability as suffering paradigm" proffered by the medical establishment, and generally endorsed by a non-disabled society. She notes that disability is "to be avoided if at all possible and women are expected to take advantage of the advances in reproductive medicine - to choose a genetically correct pregnancy". She questions the promises of genetic screening tests to improve lives: "how safe is it to assume lives are being improved? Could it be... that some lives are now harder rather than easier?" The mother of a child with Down syndrome is seen to have "brought the suffering on herself of having had choices – tests such as <u>amniocentesis and CVS</u> – but of having failed to take control, failed to prevent the suffering of her child". There is little comprehension that a mother might decide not to submit to the pre-natal genetic test, with its associated risks and consequences - the elimination of the child who is deemed to be a less than ideal choice.

Filmmaker Veronica Wain also writes of her experiences as the mother of a child with a "genetic abnormality" – 18q23 deletion. Wain, like Place, confronts the social stigma attached to disability, but finds empowerment in a supportive community, discovering in the process of making the film, what Margrit Shildrick identifies as the vulnerability shared by all human beings. Drawing on the work of Lacan, Schildrick points to the sustaining 'fantasy' of the fully realised subject in control of self – a fantasy that is one held dearly by those who identify as able-bodied:

the ideal self is phantasmatic, fissured by misidentification, and deeply threatened in its discursively constructed security by the materiality of the anomalous body, in whom signs of disorder and dependency evoke intimations of what has been disavowed. (342)

It is the vulnerability of the able- body that is often masked/disavowed by the disabled/abled dichotomy, something which we are reminded of in Catalina Florescu's account of photographer William Yang's portraits of Allen who is dying of AIDS. Yang's series of images starkly intone the body's "mortal, gradually disabling fabric".

Fiona Kumari Campbell's exhorts us to refuse "ableist normalising dialogue", to construct a different kind of landscape, a "disability imaginary" based on the "nuances and complexities" of being in and of the world; one which eschews the fixity of absolutes. To address this is to go beyond able/disable dichotomies, to interrogate the ableist- centred narratives of the medico, social, and personal tragedy models of disability presently available, and to refuse disability as a "negative ontology". Likewise Mairian Corker and Tom Shakespeare advocate that it is time to move beyond limited ways of thinking about and understanding disability. They assert that both the "medical model and the social model seek to explain disability universally, and end up creating totalising, meta-historical narratives that exclude important dimensions of disabled people's lives and (of) their knowledge" (15). There can be no unitary or coherent model that fully represents the complexity of either disabled or non-disabled people's lives; the articles in this issue of *M/C Journal* go some way towards capturing that complexity.

References

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