

**Narrating Normalcy: Disability, Medicine and Ethics
Commentary on Stowe et al., *Journal on Developmental
Disabilities*, 13(2), 2007**

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"[T]he challenge of the brave new world depends on how we will use science, policy, history, and ethics" (Stowe, Turnbull, Schrandt, & Rack, this issue, p. 57). It is in this way that Stowe et al. conclude their simulating article, raising significant issues. In addressing their important article, I would first suggest that it is not so much how we will "use" science, policy, history, and ethics. Rather, it is how we will, as moral actors and society, choose to shape them. Second, the literature in the social sciences in general, and in particular those in the history and philosophy of science, point to the way in which our notions of science, policy, history and ethics are not static or value neutral. Rather, they are shaped in accordance with power relations and social norms. The literature in Critical Disability Studies points to the way in which such knowledge systems may be seen as disabling (Oliver, 1996).

Within the Australian context, I have participated in an exploration of the way in which people with disabilities are constructed as other, outside the nice, normal and natural. That is, they are others outside of the moral community of us. This "othering" is replicated in a variety of social institutions, including science and social policy in general (Goggin & Newell, 2005). Related to this point is the very way in which ethical, legal and social issues research is funded and shaped, to a certain extent leaving untouched the highly contested nature of projects such as science and genetics (Hubbard & Ward, 1993).

Indeed, it may be seen that science – a comparatively recent epistemological concept that policy, history and ethics rely upon, and are complicit in – is narrating a highly problematic concept for people with disabilities: that of normalcy. As Leonard Davis (1997) suggested, "The problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 9). It seems extraordinary that Stowe and Turnbull do not pursue this concept, as it is crucial to the projects of science and medicine, which in turn are central to the definition and regulation of the disabled body.

Likewise, it strikes me that this article demands an examination of the marginality of people deemed to have a disability and the profoundly

negative knowledge of what it is to live with a disability. That is the meta-narrative of the tragedy of disability, which is central to the rise and perpetuation of biomedicine. Here we need to realize that disability is both central and marginal. Disability is central to the claims of science, and yet, some fifteen years since I first started writing on the impacts of biomedicine and genetics, we still see articles critiquing eugenics and talking about potential implications from the margins. Largely unaffected, the juggernaut of science rolls on remorselessly, paradoxically constructed as both value neutral and yet inherently good (Newell, 1999). Hence, in our analysis of the role and the rise of genetics we need an account of power (Newell, 2003; 2006). Dare I suggest one that talks of eugenics in more than the past tense, but recognizes the insidious nature of developments and the claims of serious scholars to an even more pervasive eugenics of the present and future (Lynn, 2001)?

In all of this, we would do well to heed the words of a narrative theorist, Hilde Lindemann Nelson, who wrote of the importance of the narrative in disempowering communities and yet of the potential for them to engage in a process of narrative repair. As she observed:

How freely we can exercise our moral agency is contingent on a number of things. Most broadly, it depends on the form of life we inhabit: the niche we occupy in our particular society; the practices and institutions within the society that set the possibilities for the courses of action that are open to us; the material, cultural, and imaginative resources at our disposal; the constraints arising from the moral flaws within our roles and relationships; the shared moral understandings that render our actions intelligible to those around us. More specifically, the extent to which our moral agency is free or constrained is determined by our own – and others' – conception of who we are. (Nelson, 2001, p. xi)

Finally, I would question the uncritical use of the notion of a "brave new world" which was not, as suggested, envisaged by George Orwell in *1984*, but by Huxley in his influential *Brave New World*. Whilst both books are dystopian, in *1984* we see people controlled via inflicting pain and suffering, whereas the *Brave New World* utilizes pleasure. There is no doubt that both novels have much to teach us about the avoidance of such a situation. It seems ironical that the authors would use the "brave new world" concept in such an uncritical way, given its use within the literature. As Fukuyama (2002) suggested, we do not have to accept such accounts of science and social policy as inevitable, being wary of technological determinism. I

cannot help reflecting, as a person with a disability, that it is time for us to move beyond responding and identifying potential issues from the margins. We certainly need people with disabilities and their advocates participating as valued equals at social and science policy decision-making tables at the highest level. Likewise, we need these people to be involved in major social initiatives that address and correct the narration of normalcy, complicit in the perpetuation of disability in such negative ways. It would be a move towards shaping what was envisaged by the authors: science, genetics and medicine respectful of all.

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