

Further reflections on biological citizens and social model stalwarts: Question of biology, ontology and human worth

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Introduction

In 2009, I wrote a paper, published in the journal *Disability & Society* entitled; *Disability activism: social model stalwarts and biological citizens*. The paper was an attempt to argue that disability activism was bifurcated into two distinct camps and that these camps were clearly divided in their respective views as to the meaning, import and vision of the past, present and future for disabled people. This paper revisits the 2009 piece and constitutes some further reflections on it. In particular, it examines the credentials of biological approaches to disability and citizenship and critiques the concepts of humanity that underpin them, pointing to the dangers that they embody and to some of the more nefarious practices that are associated with the reduction of disability to biological perspectives. The 2009 paper was analytical. This paper is much more evaluative, drawing out the kinds of social practices and forms of mis-recognition or invalidation that go hand in hand with biological accounts of disability and the reduction of the meaning of disability to impairment. The evaluation of the efficacy of the two activisms that I propose in this paper requires an extension of their distinguishing elements to include their underlying ontological assumptions. In 2007, I wrote another paper for *Disability & Society* entitled: *Being disabled: towards a critical social ontology for disability studies* (Hughes 2007). In the paper, I argue that disability scholars need to problematise non-disability and the non-disabled imaginary; that is the ableist schemas that inform dominant perspectives about what it means *to be* disabled. These perspectives, I suggest, can be profoundly invalidating. In this paper, I argue that the notion of biological citizenship is one such perspective and it continues a long tradition that supports the view that disability is '*what not to be*'.

Summarising the competing activisms

The quotation below from the 2009 paper on disability activisms offers an overview of the difference between social model stalwarts and biological citizens:

We are beginning to witness a bifurcation in disability activism in the UK. On the one hand, we have the DPM (*Disabled People's Movement*) that developed out of the ideas and activities of the Union of Physically Impaired against Segregation (UPIAS) in the 1970s. It drew sustenance from the Independent Living Movement (ILM) that started life in Berkeley, California, in the 1960s. It acquired theoretical maturity in the writings of Vic Finkelstein (1980) and Mike Oliver (1990) and developed into a credible political force – organised primarily around the activities of the British Council for Disabled People (BCOPD) – in the 1980s (Campbell and

Oliver 1996). On the other hand, we have a disparate group of ‘social movements in health’ (Brown and Zavestovski 2004). These are composed of what we have called biological or genetic citizens, some of whom claim citizenship in the name of a diagnostic category or condition. As they have come together they have developed a variety of patterns of self-help that include campaigning for recognition and resources to improve the lives of those who suffer from the condition in question. While the latter is ‘in health’ and constituted by ‘health users’ groups, the former is not. The DPM rejects the conflation of disability and sickness and disaggregates disability and chronic illness (Hughes 2009: 681-2).

I use the table below to map out the key difference between the two forms of activism. It also serves as a summary of the key distinctions between the paradigms that were developed in the 2009 paper.

Social model stalwarts	Biological citizens
Social model (Disabled People’s Movement DPM). Domain or field of activity is politics. Focus is on justice and rights for disabled people and the elimination of barriers to the inclusion of disabled people in social and cultural life. The DPM focuses on social problems and political solutions	Medical Model (Condition based interest groups): Domain or field of activity is health care. Focus is to support sufferers from specific conditions and encourage medical research and the search for cures. Biological citizens (in their biosocial groups) focus on health problems and medical solutions
Focus on the dismantling of disablist forms of social organisation.	Focus on the amelioration of bodily deficit.
Somatophobic, collectivist approach to disability issues. Not interested in the body	Centred on somatic individuality and the correction of vital deficits
Basis of solidarity, community, association and collective action is (consciousness of) the common experience of social oppression and exclusion amongst disabled people	Basis of solidarity, community, association and collective action is biological similarity and common diagnostic label; hence the possible epithet ‘biosocial groups’
Social basis for identity: In their common cause social model stalwarts use sociological and historical language and knowledge to establish the case that disabled people have been subjected to oppression, discrimination and exclusion.	Biological basis for identity: In their common cause biological citizens use biological and genetic language and knowledge to self-identify and therefore to establish their credentials as biological or genetic citizens (Heath, Rapp and Tausig 2003)

<p>Social modelists have formed a movement of emancipation embodying self-identity with the Disabled People's Movement</p>	<p>Biological citizens form condition based movements embodying self-identification with a particular disease</p>
<p>Social epistemology, understanding disability in terms of social disadvantage and purporting the irrelevance of medical knowledge, treatment and cure: The DPM also values the experiential knowledge of disabled people</p>	<p>Medical epistemology, understanding impairment in medical terms and valuing objective, medical knowledge and the research that it supports in the search for treatments and cures</p>
<p>Sceptical of genetics arguing the case that it constitutes a new form of eugenics: 'genetic fundamentalism' is a 'naturalist mythology that justifies social discrimination and exclusion' (Le Breton 4004: 15)</p>	<p>Pro genetics and genomics arguing for genetic research: Genetic technologies will bring tangible health benefits that will help people with currently incurable medical conditions</p>
<p>Anti- medicine: medicine is the enemy, a reactionary force: Social model stalwarts challenge the social basis of their 'pathological' status treating their bodies as sources of pride</p>	<p>Pro-medicine: medicine is a partner and the source of progress. Biological citizens embrace their pathological status but seek remediation towards its extirpation by way of medical and genetic technologies</p>
<p>Politics of scepticism: The promises of medical and scientific progress are to be taken with a pinch of salt. The DPM emphasises the history of promised cures that came to nothing.</p>	<p>Politics of hope: Patient self-help groups that seek recognition as certain kinds of biological citizens 'invest hope, political capital, their own tissue samples and money in the search for genetic treatments' (Rabinow and Rose 2003).</p>
<p>Pessimistic: The DPM tends to have a dystopian view of medical and scientific progress and is likely, for example, to draw attention to the links between eugenics and the new genetics, emphasising the continuity between the latter and the former:</p>	<p>Utopian: the benefits of biotechnology are legion and the health dividends or 'health use-value' (Waldby 2002) associated with genetic knowledge is potentially more potent than any advance in human history</p>
<p>Historical memory: Biology for social model stalwarts refers to 'what has been and what is', to the historically accumulated injustices that have invalidated (and continue to invalidate) the lives and bodies of disabled people. The future belongs to social change and</p>	<p>Future orientation: 'Increasingly biology refers to what might be' (Frank 2003: 262). The claim is suggestive of a (coming) post-human society in which living organisms can be modified and manipulated in significant ways. Biological citizens are aligned with this</p>

barrier removal	frame of reference.
Disability: Social oppression	Impairment: bodily deficit

The question of ontology

Let me speak to you now, more directly, as professional practitioners working with disabled people. What I have identified in this paper is not just a bifurcation in the politics of the contemporary disability movement, particularly in the context of the UK but a more enduring bifurcation in the epistemological - and more importantly from the perspective of this paper, ontological - basis of social policy, social welfare and professional practice.

Welfare systems in the modern period have been, since Bismark's day to the present, grounded in both biological and psycho-social perspectives on humanity and human need (Fuller 2011) and on this same battleground the struggle to understand disability has unfolded. Are welfare professionals, as well as the services that they provide and the systems that contextualise that provision servants of physical/biological need or social and emotional need? The medical model has (and continues to) privilege the former and the social model of disability has (and continues to) privilege the latter, not only epistemologically but also ontologically. The normative question about which ontological dimension of human being, I believe, should be privileged, is implicit in the paper so far but will unfold more explicitly as the argument develops.

I lay emphasis on the social dimension of ontology but not entirely to the detriment of the former. Professionals in the field of disability must be willing to attend to the biological as well as social and emotional needs of their clients and it is impossible to conceive of a system of welfare that is not, in some basic sense, driven by bio-material need; the imperative to clothe, to shelter to feed the population, to ameliorate, poverty, squalor and want. Of course, such an imperative also serves psycho-social well being. Consideration of physical and biological need is also a necessary condition of welfare provision because the principles of justice cannot allow us to reduce human need to a singular ontological dimension, nor to set aside either physical suffering or social oppression, no matter which dogma or ideology presses us to do so. It is just as unjust to ignore physical suffering as it is to ignore social exclusion or discrimination. Citizenship is both biological and social and therefore to maintain a radical distinction between impairment and disability or to contend that impairment is not social or disability not embodied (Hughes and Paterson 1997) is to misconstrue the political complexities that underpin the ambitions of the 'last civil rights movement'.

Yet an important caveat is required and I will linger long on its import and consequences. When biology underpins concepts of citizenship and practices of

welfare – particularly in relation to disability - not only does it fail, in many cases, to serve justice but it can become a compellingly invalidating force. The impact of eugenics on UK, US, German and Scandinavian social policy, particularly in the first half of the 20th century, is the case that comes most immediately to mind as an example of human rights squandered and human lives destroyed when citizenship is reduced to biological imperatives. Biology is a particularly precarious and dangerous basis for citizenship and policy development and its ontological prioritisation in notions of what constitutes human worth, value and virtue has notorious consequences for disabled people.

- 1) Graeco-Roman culture: Herodotus – the father of History - claims that the first and most important credential for human well being or *eudaimonia* rests in ‘freedom from deformity’ (Quoted in Shapiro 1999: 153). Furthermore, virtue or excellence – what the Greeks called *arete* – rests on the possession of a sound mind in a sound body. The ranks of humanity, not to mention citizenship, are therefore, confined to those who can demonstrate the aptitude for physical perfectability and partake of the curricula for excellence that grounds the development of the faculty of reason. Aristotle’s ‘virtue ethics’ are founded on ableist assumptions, on the view that goodness, beauty and truth are part of the package of what makes for a virtuous life and that physical beauty is the outward sign of a life well lived. The disability historian Robert Garland (2010: 12) remarks that the classical perspective on the body was markedly prescriptive and narrow: ‘Any departure from the ideal type, however trivial, was ... interpreted as a mark of the despised barbarian, whose attributed physiological defects were regarded as an expression of the latter’s cultural limitations’. Biological criteria, therefore, make it plain that disability and barbarism go hand in hand. The gloss for this view is well developed in book 4 of the *Generation of Animals*, in which Aristotle argues that if the natural template for humanity is male biology, then women are ridden with defect and that a child born with a physical anomaly ‘appears ... to be not even a human being but only some kind of animal, what is called a monstrosity’ (Aristotle 2007: book 4). The theoretical desire in the early tradition of western philosophy to exclude disability from the ontological cradle of humanity is most clearly articulated in Plato’s eugenic sentiments. He advises that infanticide is the best possible solution for disabled newborns, that if the life taken is not worth living, or indeed, not worthy of living, then ‘its’ peremptory termination is a moral duty. ‘And those of the worst’ declared Plato in *The Republic* (Bloom 1968: 139), ‘and any others born deformed, they will hide away in an unspeakable and unseen place, as is seemly’.
- 2) Bind people in medieval society: In his book on *Medieval Constructions of Disability*, subtitled, *Stumbling Blocks Before the Blind*, Wheatley (2010) examines representations of blind people in Medieval France and England

where responses to disability range ‘from Christian charity to violent humiliation’ (p. 4). Stereotypes of blind people are ubiquitous and abound in cruel literary representations of blindness, much less so in England than in France where the tradition of blinding people as punishment was well established. The stereotypes of blindness in the medieval non-disabled French imaginary include, *inter alia*, the following: Blind people are stingy, miserly and greedy (pp. 92; 102; 107); practice sexual excess (p. 82) including sodomy (p. 92); are prone to gluttony (p.97); are false mendicants who fleece decent folk for their hard earned wealth (p. 93) and – most curious of all – are prone to committing arson (p. 94). In this litany of moral perfidiousness, a number of the cardinal sins are attributed to blindness. The association of blindness with moral degradation makes it easy – even right – for the sighted community to make fun out of and to satirise blindness and the wits of the day did not miss the trick. For the entertainment of the audiences attending medieval farces and plays, ‘blind characters are subjected to physical abuse and cruelty *because* of their blindness’ and disability is performed ‘in a degrading manner’ (Wheatley 2010: 128)

- 3) Reformation: During the reformation, disabled children were sometimes – through the supernatural hermeneutic of folklore and folk beliefs - regarded as changelings. Such ‘persons’ came to play a role in the construction of disability by the protestant reformers. In Martin Luther’s view changelings were manifestations of the work of the devil. He notes that in the case of changelings, ‘the devil sits ... where the soul should have been’ (Quoted in Garland 2010: 16). Luther offers up to posterity a stunning theological representation of the devil in the form of a disabled child. Luther encountered a 12 year old boy who appeared to be limited in his abilities to basic animal functions. He made reference to this child in a biblical commentary of 1535 and in discussions with fellow clergy in 1540. The child was a base and fleshy creature, asocial and animal like in manner, and, therefore, he concluded an improper receptacle for a soul. He saw in the demeanour and comportment of the boy the work of the devil who had acted with characteristic malice and evil, ‘to remove a child completely and put himself into the cradle in place of the stolen child’ (Miles 2001: 30-31). In the myth of the changeling we witness the transportation of disability to an otherworldly dimension; a trope that takes it out of humanity and places it in a world inhabited by devils, fairies and trolls. Impairment is an imposter in the universe of men and women, an alien being from another world that relocates itself in the space occupied by a once human form, taking on that form in an act of diabolical deception. Such a ‘creature’ is more than a mark of the practices of the devil. The changeling is evil incarnate, the demon made flesh. In this particular case the form attributed to impairment is regarded as entirely non-human. Impairment is only the material appearance of an underlying ontology that hails from a brute,

ignoble and satanic world that we can only conjure up in our imagination. It is ontologically reclassified as a thing that is not commensurate – qualitatively, in its essence, in any ‘real’ way, shape or form – with the human species. The superstitious hue of the non-disabled imaginary has finally found a way to make disability come from a place so nether and remote that no human could ever tread. Luther has postulated the final frontiers of disability invalidation, somewhere, way, way over the rainbow. The contemporary world reprises this trope – of the alien other - with a curious ‘secular’ equivalent, manifest in the space that autism sometimes fills in the non-disabled (or neurotypical) imaginary and indeed in the minds of some commentators who are themselves autistic. The alien, from the genre of science fiction, is used with surprising regularity to represent the autistic mind and the difficulties of communication that exist between autistic people and neurotypicals (Hacking 2009). It is as if the mutual impenetrability of the two parties refers to cognitive differences so great, so far removed from the possibilities of human empathy that autistic people must belong to some kind of extra-terrestrial species.

- 4) Eugenics and modernity: Snyder and Mitchell (2006: 101) argue that: ‘From the end of the eighteenth century to the conclusion of World war 11, bodies designated as defective became the focal point of European and American efforts to engineer a “healthy” body politic. While fears of racial, sexual and gendered “weakness” served as the spokes of this belief system, disability, as a synonym for biological (or in-built) inferiority, functioned as the hub that provided cross cultural unity’. Biology – particularly the theory of heredity - is the servant of eugenics and the threat that some ‘defective’ bodies and minds are thought to pose to the integrity of the whole population form the political backbone of the genetics movement. Although the targets for sterilization, marriage or immigration laws or whatever legal form eugenics has taken – including the Nazi euthanasia movement – are most often people with intellectual or cognitive impairment, physical concepts of hygienic embodiment play a significant role in marking those who are deemed unfit to participate in the human community: ‘Eugenics ... emphasised the relationship of physical “stigmata” to cognitive inferiority and in doing so, provided mechanisms for analysing the visible surface of the body as an indicator of an otherwise intangible interior defect’ (Snyder and Mitchell 2006: 118)
- 5) The Human Genome Project: Who can doubt that the Human Genome Project is not motivated by a teleological reflection on the possibility of human perfection, the continuous striving after betterment of body and mind: A movement towards an eschatology, no longer religious but secular, in which the destiny of man is finally realised and the errors of nature corrected. There is, in the view of bioethicist John Harris (2007), a strong ethical case for making better people, for enhancing evolution through the use of

biotechnology. He applauds the possibility of the transformation of man into superman and argues that genetic engineering and even the production of designer babies is a moral obligation. The idea – the hubris – that humanity might, indeed should, master its own nature and that it is our duty to aspire to and work towards such an end, is not exactly new. Augustine’s doctrine of ‘*imago die*’ – man born in the image and likeness of God – posits humanity as potentially a perfect unity of the two substances of mind and body; a potential that will be realised at the end of the world and the ‘perfectable self’ is evident in the ambition of Greek citizens to strive for soundness of mind and body in order to achieve *Eudaimonia*, in order to ape the gods and the good life that such deities represent. In Harris and in the illustrious ideas and practices of his predecessors we can detect the manifesto of ableism and the erudite splashes of justification for the ontological invalidation and elimination of disability.

History lessons

- 1) Historically, a biological basis for identity and action – the reduction of disability to impairment - has been imposed on disabled people by a variety of moral authorities, to the detriment of disabled people’s life chances;
- 2) Amelioration of bodily deficit assumes religious, medical and aesthetic binaries that have been used throughout history to extinguish impairment;
- 3) Normalisation – particularly biological normalisation – as a catalyst for the erasure of physical difference has proved, consistently, to be a poor judge of human worth;
- 4) Deficit models of disability are largely a product of the historically specific form of the non-disabled imaginary;
- 5) The futurist orientation of biology may turn out to be more dystopian than utopian since it seems to be grounded on the ableist aspiration of human perfectability.

Conclusion

Ableism is the product of the cognitive content of the non-disabled imaginary. It is the moral architecture associated with the hegemony of able-bodied ways of doing and thinking and the carnal priorities that are designed into the social fabric that informs the built environment. Campbell (2008: 153 and 2009: 5) defines ableism as, ‘a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical and therefore essential and fully human’. Ableism, therefore, refers to the ways in which

cultures (varyingly) prioritise the illusion of normative wholeness, promote a corporeal standard, encourage aspirations towards it and, in so doing, make disability its illegitimate offspring, its denigrated other, a form of invalid being. Ableism disqualifies 'groups of people based upon what is characterised as biologically coded insufficiency' (Snyder and Mitchell 2006: 126-7). If contemporary activists are to position themselves appropriately to advance the cause of disabled people, they must situate themselves in ways that critique the contours of ableism. The ideas and practices associated with contemporary forms of biological citizenship are, however, easily assimilated into the ableist imaginary, accepting both in principle and practice that disability is an undesirable ontological condition that needs to be ameliorated and corrected through the use of genetic, medical and scientific technologies. Biological citizenship is a form of disability activism that is prone to accept disability as 'the master trope of human disqualification' (Mitchell and Snyder (2006: 125-29)

Ableism embodies the story of a dynamic, interacting binary couple, namely disability and non-disability or disability and abledness (Campbell 2010), an abusive and dysfunctional relationship in which the latter – the dominant partner – has acquired the reputation for validity and worthiness whilst the former has lived in a shadow state in which worth is seldom recognised and validity constantly undermined. Being disabled has involved a struggle for recognition and respect; a permanent war against the othering of difference, against the construction and placement of impairment and its army of proxies - deformity, defect, monstrosity, anomaly, insanity - into a category of ontological, aesthetic, social, cultural and ethical dubiety as well as a source of psycho-emotional threat to the normative condition of wholeness.

It is ironic that in a time when it is commonplace to debate post-humanity and trans-human futures that some people are still struggling, not only for the opportunity to enter the ranks of wage-slavery but to prove their worth as fellow *homo sapiens*. We seem to be, once again, becoming more determinedly biological in our notions of citizenship (Rose 2001; 2007; Rose and Novas 2004) reiterating the values of Hellenic, Medieval and Victorian predecessors as we become seduced by genomic discourse whilst on the other hand, minority groups draw attention to the invalidating consequences of biopolitics and the lust for biocapital. For people who are comfortably associated with animals – appearing liberally as 'mediators' in the literature on animal liberation (Carlson 2010) - and some for whom the epithet 'vegetable' is thought appropriate, fellowship is not handed out in the easy, taken for granted manner that most might expect as a birth right and the political accent on biology becomes a fundamental political challenge.

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