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Imagining Disability Tomorrow

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Abstract

Drawing upon the insights of disability studies in terms of the present situation of people with disability we propose an imagining of disability as an integral and positive part of an Australasian university. This offers a challenge not just to the academy but also to future studies, in conceptualising disability in accordance with a human rights perspective acknowledging the structural nature of disadvantage and oppression.

Imagining Disability Tomorrow

In this article we seek to do something fundamentally disturbing and counter-cultural: to imagine disability in the future, with a particular focus on how it could occur in an Australasian university department. Often when disability is imagined in the future it is largely by non-disabled commentators who focus on scenarios whereby people with disabilities will be potentially delivered by the technological genie. In this piece we take a radically different imagining, based upon several important differences. First, most unusual still for writing about disability, one of us (Newell) identifies as having a disability. In the second case, we would suggest that disability will always exist especially when we adopt a cultural understanding of the creation of dis-ability. Hence we wish to move from the discomforted gaze which often finds reassurance in the bio-tech cures just around the corner, to a perspective which recognises that the future construction of the disabled body and mind is largely a symptom of the power relations of disability (see for example Goggin & Newell 2005).

Understanding Disability Today

Despite the fact that approximately one in five of the world's population lives with disability there is still a significant gap in the literature, in imagining disability futures based upon the human rights of people with disability, and especially the rights we have to develop as full human beings. Not only have futures projects largely ignored disability or failed to explore its social and political dimensions (Newell & Wilkinson 2003) but we would suggest that the diverse community of people with disabilities, their carers and families have largely not attempted imagining the future in this way. In part, this is because of the current situation of people with disabilities.

Elsewhere we have analysed the creation and perpetuation of disability in its social context (Goggin & Newell 2003; 2005). Some 25 years after the International Year of Disabled Persons (IYDP) was supposed to have delivered us from disability with the ground-breaking slogan "Breakdown the Barriers" we would suggest that many of the negative attitudes and structures which create and perpetuate people with disability as "other" remain. As the late Kathleen Ball commented in summing up Australian society in 2001:

We have made some legitimate gains in terms of physical access but the real problem is yet to be fully addressed. Negative attitudes towards people with disabilities are rife in the community. If we are to achieve any sense of true emancipation, we must fight attitudinal barriers to equal participation in all aspects of community life. Nothing is really going to change until we do ... Our lives are governed by legislation. Carers refuse to handle our bodies without the protection of latex ... our bodies remain the property of those who lift, dress and wipe. Women with disabilities continue to be sterilised and when we do reproduce, over one third of our children are removed from our care. Quite often, our pregnancies are terminated against our will. We are raped by institutional staff and yet forbidden to engage in consensual sex. Our finances are managed and our lifestyles are regulated by duty of care. (Ball 2001)

In our 2005 analysis of Australian society we have identified this as a form of social apartheid, seeking to look at the taken-for-granted reasons as to why those of us with disability so routinely need special accommodation, special education, special transport, even special access based upon that dominant construct "special needs". We locate ourselves within that critical emerging trans-disciplinary endeavour, disability studies, which identifies the treatment of people with disabilities in terms of oppression (Abberley 1982) and suggests that this may be viewed in terms of disablism, a largely unrealised oppression similar to racism and sexism. As Mike Oliver argues with

regard to disablism:

If the category disability is to be produced in ways different from the individualised pathological way it is currently produced, then what should be researched is not the disabled people of the positivist and interpretive research paradigms but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society. (Oliver, 1996:143)

In our experience such a situation can also be seen within the academy which increasingly features under-graduate students with disabilities but where they are lucky if they have a job at the other end. Indeed for all the rhetoric of equal opportunity Universities largely fail to address the disablism inherent in taken for granted structures which mean is still very rare to find senior academics with disability. Sadly we also find that in many disciplines there is still significant theoretical work to be done. In the forthcoming scenario we offer an alternative imagining of disability in the future in a university department.

Disability in 2010

It is the year 2010. The Department of Communication, Cultural and Media Studies in an Australasian university is bustling. Jane, a Deaf professor who uses sign language as her first language, is teaching a graduate class. Scholars come from around the world to rethink - and re-imagine- communication, and dominant western approaches with this scholar. Her work is inherently integrated within the Deaf community, where Auslan (Australian Sign Language) is the dominant language, and those without sign language as their first language are the ones who need interpreters. John is an associate professor with intellectual disability, speech impairment and a variety of other medical labels previously used to institutionalise him. His experience of disability, institutional and supported communal living, and the experience of being 'other' provides crucial opportunities for complex understandings of the world, diverse research questions, and reconceptualiz-

ing communication, with new understandings of identity, culture, and power. Non-disabled discourses, images, norms, tropes, and structures have previously dominated in the face-to-face and virtual worlds (Davis 1995; Mitchell & Snyder 2000; Barnes & Mercer 1986), but John's work is opening up new spaces of dialogue, exchange, and collaboration. John shares his position with another person as they team-teach, a significant opportunity for those who need flexible or fractional work.

This trans-disciplinary department lies within a University which routinely asks what members of the University community need for functioning, and provides the communication facilitation, attendant and personal care and other support, seeking to integrate these with community support, avoiding cost-shifting in placing the burden of such costs upon the individual or their family. The University even successfully mounted a High Court challenge recently, which turned around government policy regarding academic output, in light of the previously restricted and disablist ways of assessing and counting productivity for funding purposes. Significant research projects are conducted with, and within, diverse communities, with which the University has equal and continuing relationships, as well as in the everyday interactions on campus, with the virtual communities fostered within the department, and with the wider community. Disability, and Deafness Studies have become essential parts of the teaching and learning as well as the research program.

Along the way some significant learning has been necessary for all parties. Scholars and students with disabilities that once-upon-a-time would either have been regarded as being worthy of institutionalisation or certainly 'non-productive' have had to rethink some of the ways in which they have been socialised. Other people with largely hidden impairments (the vast majority of the population of people with disabilities) have come to claim their experiences of disability as important knowledge and to name the complexities of their situation. The University has had to rethink its approach to disability as requiring "inclusion", recognising

that this ethos left untouched a variety of disablist ways of working, and the structural and ideological reasons behind why people needed to be "included" in the first place. In the process a variety of communication and special education scholars had to rethink the norms utilised in their work.

The "otherness" of disability has moved from being an interesting but peripheral research question to being a central activity in the humanities and in the University (Snyder, Brueggemann & Garland-Thomson 2002). Problems with communication become something which is not blamed on a deviant individual's body but opportunities for new insights, new ways of thinking, new ways of imagining disability and communication. (Corker & Shakespeare 2002). Disability and power is incorporated in the curriculum at all levels, taught by teachers with disabilities, as well as informing the work of temporarily able-bodied colleagues, recognising that throughout our lives, especially as we age, most people will acquire some form of impairment. There are now a number of important doctoral theses underway informed by critical disability studies. Cultural and media studies scholars and students in the University work with practitioners and policy-makers in creative, cultural and media industries around disability and diversity matters. Despite the fact that its research and teaching is challenging, the Department has managed to move from every year being threatened with closure because of the disturbing nature of its work for the state, and indeed some parts of the diverse disability community, to conducting online courses and seminars which teach critical thinking policy and practice skills to a variety of stakeholders, including bureaucrats and senior academic administrators.

Through the direct relationships which are fostered, all concerned have come to learn of disability as far more than an individual's medical deficit requiring a charitable response. (Fulcher 1989) All in this University have come to understand the social and cultural nature of disability, its messy interweaving with other social categories of class, ethnos, race, gender,

sexuality, colonialism and empire. In this way the interrelationship of disability with communication, culture, and media in their broadest senses is routinely embraced and explored (Mitchell & Snyder 2000).

Discussing all we imagine

In this utopia we have deliberately conceptualised a future of disability in a way which may seem deeply unrealistic. Yet it is a logical extension of our own work, and disability studies in general, as applied to communication, cultural and media studies (Goggin & Newell 2003; 2005) Communication, cultural and media studies have significant opportunities to foster new cultural representations of disability and indeed to help people with disability and wider society to understand our place within society (Gallois 2003), as do the wider humanities and social sciences.

Yet, rather than some grand scenario being the end point, we would suggest that it is in the day-to-day relationships of scholars with people with disability, and as these two groupings become indistinct through mixing, that we will foster the ending of disability as "other", finding ways of deconstructing and representing disability as part of "us" in a diverse community. Our conception of a Department of an Australasian university goes beyond integration, to a routine embrace of disability as a key area of cultural inquiry and litmus test of social policy. It is one where the Academy sees significant responsibilities to assist key cultural and social institutions such as the media to conceptualise disability within a diversity framework which enables rather than oppressing.

Such imagining provides fundamental challenges for the everyday role and practices of universities. This involves embracing the challenges associated with the routine requirements of disability as crucial opportunities for teaching and research. It also requires purposefully working with diverse communities, and challenging established practices of the State and professions which today routinely appropriate disability to their ends (see for example Albrecht 1992). New and diverse forms of cultural representation of disability will only come via purposeful and mundane relationships which move disability from the exotic to new ways of understanding personhood, nationhood, community and even the goals of life and living itself. This is an inherently politically dangerous as well as creative exercise, which involves reinventing the meta-narratives and institutions of disability, nationhood, and the Academy.

Making Tomorrow a Reality

It would be easy to dismiss such a futuristic piece as unworkable, unrealistically utopian. Yet, we would suggest that for the future situation of people with disability to be improved requires more than just the exploration of the cultural and structural nature of disability within institutions such as universities. It also requires the purposeful introduction of a variety of scenarios regarding disability into future studies. Rather than imagining disability in the future as inherently a matter of medical and charitable approaches, there is much to be said for an imagining of the future based upon the inherent human rights of all people, including those society regards as disabled.
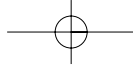
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References

Abberley, Paul. 1992. "The concept of oppression and the development of a social theory of disability" *Disability, Handicap and Society*. 2: 5–19

Albrecht, Gary L. 1992. *The Disability business*. Newbury Park: Sage.

Ball, Kathleen. 2001. "We don't live in our homes, we live in our carers' workplace". *Link Magazine*. 10 (4): 14

Barnes, C. & Mercer, G. Eds. 1986. *Exploring the divide: illness and disability, University of Leeds.* Leeds: The Disability Press.

Corker, M. & Shakespeare, T. Eds. 2002. *Disability/postmodernity: embodying disability theory*. London: Continuum.

Davis, L.J. 1995. *Enforcing normalcy: disability, deafness, and the body*. London: Verso.

Fulcher, Gillian. 1989. *Disabling policies?: a comparative approach to education, policy, and disability*. New York: Falmer Press.

Gallois, Cindy. 2003. "Disability diversity matters". *Australian Journal of Communication*. 30 (3): 167-71

Goggin, Gerard & Newell, Christopher. 2003. *Digital disability: the social construction of disability in new media*. Boulder, Colorado: Rowman & Littlefield.

__. 2005. *Disability in Australia: Exposing a social apartheid*. Sydney: UNSW Press.

Mitchell, David & Snyder, Sharon. 2000. *Narrative prosthesis: disability and the dependencies of discourse*. Ann Arbor, MI: University of Michigan Press.

Oliver, Mike.1996. *Understanding Disability From Theory to Practice*. Houndmills, MacMillan Press.

Snyder, S.L, Brueggemann, B.J. & Garland-Thompson, R. Eds. 2002. *Disability studies: Enabling the humanities*. New York: The Modern Language Association of America.