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open space

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slow life and ecologies of sensation

Anna Hickey-Moody

This piece is a mobilisation of, and response to, Puar's timely rejuvenation of the idea of debility. I explore some limits of Puar's (2009, 2012) take on debility, arguing for an ecology of sensation as a methodology for thinking and feeling through what I call a political economy of 'slow life'. Thinking through slow lives, those lived in crip time (Kuppers, 2014, pp. 51–52), is a way of valuing how 'disabled' bodies and subjectivities experience and reproduce the world. Implicit in this suggestion is the belief that disabled bodies and embodied subjectivities experience and reproduce the world in ways that show up limits in popular sensory and spatial geographies and economies. The idea of a political economy of slow life is my response to Puar's (2012) and Berlant's (2007, 2011) respective suggestions that the biopolitical control of disabled, debilitated, obese and queer populations is effected through a governmental assumption (and production) of a slow death. I also write in response to the important question posed by Goodley *et al.* (2014, p. 982), who ask, 'what alternatives does disability offer to the slow death of neoliberalism and false politics of austerity?'. In short, I propose a slow temporal ecology of sensory aesthetics that is posited by cultures of intellectual disability as a materialist critique of slow death.

Berlant's slow death is the living conditions imposed by late capitalism. The term

> refers to the physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence. The general emphasis of the phrase is on the phenomenon of mass physical attenuation under global / national regimes of capitalist structural subordination and governmentality. (Berlant, 2007, p. 745)

Through slow death, select bodies are governed out of life, but even if not for long, they live lives that I think we must think through. Strategies of governance operate partly through silencing, through killing. These premises are taken on by Puar in 'The cost of getting better', where she suggests that:

> discourses surrounding gay youth suicide partake in a spurious binarization of what I foreground as an interdependent relationship between bodily capacity and bodily debility. These discourses reproduce neoliberalism's heightened demands for bodily capacity, even as this same neoliberalism marks out populations for what Lauren Berlant has described as 'slow death'—the debilitating ongoing-ness of structural inequality and suffering. In the United States, where personal debt incurred through medical

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> expenses is the number one reason for filing for bankruptcy, the centrality of what is termed the medical-industrial complex to the profitability of slow death cannot be overstated. (Puar, 2012, p. 149)

The above statements outline the politics of the economic and social production and removal of bodies: debility, disability, and some queer lives, bodies and acts are consistently eroded by sovereign strategies of state governance. However, while the disabled, obese people and LGBTI people are certainly subject to state-sanctioned 'slow deaths', they also inhabit political and material conditions that are at least as different as they are similar. These differences matter. They entail different forms of labour and are interpolated socially and politically in diverse ways. We need to think through and acknowledge such differences and the forms of activism and everyday labour they entail.

I want to talk about the political and material conditions of bodies who are medically stratified as having intellectual disability. I want to think about these bodies as having slow lives, rather than slow deaths. The distinction between slow life and slow death I want to make is strategic, and I move on to explain this strategy in relation to Berlant's work on slow death and Puar's writings on debility below. However, here I want to very briefly characterise some problems with, and uses for, the noun phrase. The term intellectual disability covers a wide range of bodies, and is often used interchangeably with developmental delay and learning difficulty. The heterogeneity of the category can also encompass those with cognitive and sensory impairments, Down's syndrome, and in some cases autism and cerebral palsy, which can be accompanied by intellectual disability. Not all intellectually disabled bodies are visible, and there is a particular practice and politics of visual coding associated with facial and physical signifiers of Down's syndrome, which cannot be transferred onto other intellectually disabled bodies.

As a term developed within medical discourses, intellectual disability is a value judgement that does not express the strengths of those who are coded as being intellectually disabled. Medical discourses have been developed to shape and class the physical world rather than conceptualise it. Medical terms form parts of complex systems of codings that occur upon a very limited plane of reference. Any medical plane of reference is constructed through discursive systems, which Deleuze and Guattari (1994[1991], p. 118) delightfully characterise as being composed of 'functives', or elements of physical functions that are actualised within the discursive system in question. From this perspective, the term intellectual disability cannot be seen as a way of characterising or describing a person; rather, it is a limited system of coding that has incidentally become known as a way of describing people. Intellectual disability is the only noun phrase available to characterise a broad spectrum of ontological conditions. Despite its limits, inadequacies and the indisputable fact that the term intellectual disability is a medical coding that has perhaps unwisely been transferred into social and cultural contexts, the noun phrase retains some use value because it makes an ontological point: it articulates a state of being that is empirically very particular. This particularity requires attention.

In her theory of slow death, Berlant powerfully accounts for the governing out of existence that is imposed on people through certain forms of labour and on those who are not able to work (Harvey, 2000, in Berlant, 2007, p. 754). Those not able to work are defined as ill and thus left open to governmental sovereign rule, which Berlant defines through Foucault. In *Society Must Be Defended* Foucault defines sovereignty as 'the right to take life or let live' (quoted in Berlant, 2007, p. 756), and Berlant considers the everyday economies and affective labours of those whose lives are taken, those who in some instances contribute to the taking of their own lives. For example, becoming obese can be seen as a way of resisting a neo-liberal present and future. Berlant (2007, p. 756) states, 'Slow death occupies the temporalities of the endemic'; slow death is a way of stopping the progression of the unfolding of a neo-liberal future. Not living, or shortening one's own life, living in a way that defies normative ideologies about health, can be seen as a form of agency:

> Through the space opened up by slow death, then, I mean to rethink some taxonomies of causality, subjectivity, and life making embedded in normative notions of agency. More particularly, I want to suggest that to continue to counter the moral science of biopolitics, which links the political administration of life to a melodrama about the care of the monadic self, we need to think about agency and personhood not only in normative terms but also as activity exercised within spaces of ordinariness. (Berlant, 2007, p. 758)

There is a relationship here between time and life, time and death, in which agency can be inaction, stopping life or shortening life. This relationship to agency embedded in the idea that slow death occupies the temporalities of the endemic resonates with Puar's (2009) concept of prognosis time. Building on Jain's (2007, p. 79) suggestion that 'all of us in American risk culture live to some degree in prognosis', Puar considers prognosis as a measure of hope:

> Jain offers, but does not develop, the proposition that 'living in prognosis' might be usefully deployed to re-tool disability studies beyond its current imbrication in Euro-American identity-based rights politics, moving us—as she suggests—from the disabled subject to the prognostic subject, from the subject of disability to the subject of prognosis, thus changing the category of disability itself, while temporally decomposing the common disability activist mantra: 'you're only able-bodied until you're disabled'. (Puar, 2009, p. 163)

'American risk culture' as characterised by Jain can be held alongside British austerity politics and Australian conservative Liberal rule. Of course, each located politic and system of governance is context specific, yet all three governance regimes are characterised by neo-liberal discourses and practices that are affectively administered and employed to effect a form of class rule that privileges economic elites. Goodley *et al.* (2014, p. 981) describe the relationship between the American and British astutely by stating that 'neoliberalism provides an ecosystem for the nourishment of ableism, which we can define as neoliberal-abelism. We are all expected to overcome economic downturn and respond to austerity through adhering to abelism's ideals, its narrow conceptions of personhood, its arrogance and its propensity to buddy up with other fascistic ideologies'.

Prognosis time, as a neo-liberal-abelist form of governance, 'severs the idea of a time line, puts pressure on the assumption of an expected life span—a barometer of one's modernity—and the privilege one has or does not have to presume what one's life span will be, hence troubling any common view of life phases, generational time, and longevity' (Puar, 2009, pp. 165–166).

Bodies with intellectual disabilities are a specific register of 'prognosis time'. They constitute an outside to the bodies who Waldby and Mitchell (2006, p. 187) suggest have an economic value as commodities in bio-economies within which 'the wealthy can purchase the fantasy of a regenerative body at the expense of the health of other, less valuable bodies', through buying organs and infants. Having two sets of chromosome 21 makes a body unfit for surrogacy or organ trade for 'the wealthy' (*ibid.*). All forms of intellectual disability necessitate a slow life and this slow life constitutes an outside to most capitalist economies and dominant modes of experiencing and producing, or 'machining', subjectivity.

I agree that thinking through 'switchpoints of bodily capacity' (Puar, 2012, p. 151) and mapping 'ecologies of sensation' (*ibid.*, p. 150) are useful methodological tools through which we can see how disabled bodies and debility express with or articulate alongside geographies of other bodies, communities and accumulations of affect. I take these two methodological strategies as futures emerging from Puar's work to explore the possibilities afforded by the idea of slow life, and to examine the utility of ecologies of sensation for mapping, feeling, recording intellectually disabled lives.

A slow life is an expression of a non-linear, non-singular, slow temporality that is located in particular ontological states and is expressed through relations with others:

> *I need you.*
> *I need help.*
> *I'm not sure what you mean,*
> *I need more time.*
> *I don't speak.*
> *I can't see, I can't hear, I feel.*

Ontologies of difference. Profound, multiple, disabilities. Medical discourses construct social faces of people with intellectual disability through attributing particular significances to their physical features and arguing that these are signs of a specific kind of subjectivity. No space is provided here for the proliferation of alternative, relational, sense-based knowledges, durations of existence that differ from those of people without intellectual disability and for the political importance of 'being with'. Bodies with intellectual disability cannot be thought completely outside the limits of medical knowledge, as 'intellectual disability' itself is a medical construction beyond which contemporary culture still struggles to think. Along with atypical machinings of the sensorium and slow duration, people with intellectual disability have a difficult relationship to capitalism. The economics of debility and disability are complex.

Because of this, I remain invested in distinctions between disabled, queer and debilitated bodies and subjects. Intellectual disability has an especially limited economic value. I agree with Puar that the 'profitability' of disability is a useful way of contextualising the financial exploitation of those with serious medical needs, but the economics of intellectual disability are more complicated than the 'profit' generated through charging for the medical costs of people with intellectual disability. Unlike homonational subjects, or those with the possibility of becoming homonational subjects, people with intellectual disability, and indeed many forms of debility, are largely excluded from being significantly valued within capitalist economies as workers. Disability and debility are hard to commodify. They do not add value to products or places and they directly affect a body's capacity to earn.

As Puar's book *Terrorist Assemblages* (2007) shows us, homonational identities can add value to places and products in certain contexts. Homonational subjects and bodies are able to work and earn in ways that intellectually disabled people are not afforded. So there are very important distinctions in my mind between the debilities experienced in Tyler Clementi's case, which Puar (2012) outlines in her article 'Coda: the cost of getting better: sensation, suicide, switchpoints' and the disabilities experienced by, for example, a middle-aged woman with Down's syndrome. In 'The cost of getting better' Puar examines the suicide of Rutger's student Tyler Clementi in 2010. Clementi was persecuted by fellow students in Rutgers after footage of him having gay sex was circulated.

I understand the utility of showing the relationship between Clementi and his homophobic peers as based on a shared 'geekness': they all experience certain debilities in spite of the fact that some are homophobic and some are not. Taken outside the context of Rutgers, the concept of debility can also link privileged people persecuted for liking the 'wrong kind of pleasure' to, for example, the lives of people who hold no social privilege. For example, women with intellectual disabilities are still seen as candidates for forced sterilisation (Open Society Foundation, 2011), and a staggering 50–90 per cent of these women are likely to experience sexual abuse when living in care in Australia (Australian Bureau of Statistics [ABS], 2009). The forced sterilisation of women with intellectual disabilities makes them responsible for their own abuse.[1] The concept of debility is less useful when it serves to erase, rather than highlight, the differences in ecologies of sensations experienced by bodies. The life of the white gay man at an Ivy League university is sensorially and affectively very different to the life of a woman with intellectual disability living in a group home and being sexually abused by a carer. So I am suggesting that a concept that brings together the ecologies of sensation experienced by such bodies, rather than examining the different kinds of emotional, physical and political labour these bodies undertake in maintaining life, seems to overlook the specificity of sensation. We need to understand and value the different ecologies of sensation through which diverse modes of debility are articulated.

Building on her re-reading of Rai's (2009) 'ecologies of sensation', Puar (2012, p. 151) argues that affective activism presents an engaged, critical future through which we can map 'switch points of bodily capacity'. This, to my mind, is a more useful concept than debility, as affective activism can be employed to think about how intellectually disabled bodies 'turn on' or activate switchpoints or affects in other bodies, through which they create 'ecologies of sensation' (*ibid.*, p. 150). Embodied relations, sensory experiences and, as I argue elsewhere (Hickey-Moody, 2006, 2009; Hickey-Moody and Crowley, 2011), art made by and with people with intellectual disability can fracture and redesign despotic, medical and capitalist codings of intellectual disability. As I argue in *Unimaginable Bodies* (Hickey-Moody, 2009), the process of devising and performing integrated dance theatre kinaesthetically reconfigures dancers' embodied subjectivities. Through creating and performing affects that engender audience responses of curiosity, desire, awe, surprise and laughter, dance theatre can build relationships between intellectually disabled and non-disabled people in which intellectually disabled people are interpolated as desirable, useful, humorous, powerful: a spectrum of affective responses not commonly attached to bodies with intellectual disability in the public pedagogies of intellectual disability disseminated by popular film texts (e.g., *Memory Keeper's Daughter, Down Side Up*) or advertisements (Care.Com, Target, Benetton), which tend to attach affects of pathos to the intellectually disabled body, typically represented as a young person.

The difference between being looked down on, being spoken down to and being respected, admired, wanted is a visceral sensation that is mapped through experience. These different kinds of relation map different ecologies of sensation, which are diverse accounts of (or lack accounting for) the work that people with intellectual disability have to do to live, the humour and resourcefulness they bring, their

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[1] In suggesting that women are made responsible for their own abuse I mean the women are physically made to bear responsibility for their own abuse, as being sterilised means they can be abused without pregnancy, which would be evidence of the abuse.

strengths and skills. Being seen as a strong and skilled member of society clearly makes one feel differently about oneself than being seen as one looked down on. Such differences in relational ecologies of sensation effect different processes of subjectivation.

These processes of subjectivation are corporeal changes that alter the ways people with intellectual disability know themselves and become who they are. Recognising the everyday labour of people with intellectual disability, understanding, appreciating and respecting them, being with them, remains a critical, political strategy. It is how ecologies of sensation that appreciate, respect and acknowledge people with intellectual disability can be made and through which they can activate switch points of bodies without intellectual disability. Through a focus on practical, embodied relations, we can map the activation of difference in non-disabled bodies and this may lead to an everyday, yet hopefully substantive, possibility for the critique of limiting discourses of the social and medical construction of intellectual disability.

Here, ecologies of sensation becomes a methodology that is inclusive of ontological truths, yet does not feature the word 'intellectual disability' and thus does not reproduce a distinction between mind and body. The productive, affective embodied labour undertaken by people with intellectual disability is critical within ecologies of sensation, and the methodology is the practice of valuing their work as productive. As a materialist methodology, living and thinking through the ecologies of sensation created by artists with intellectual disability offers a means of both addressing the problem of how intellectually disabled people are perceived and changing it through creating new forms of understanding and modes of experiential perception. Here, methods are a form of activism that allows us to bring out and appreciate modes of being and practices of relationality that are not yet perceptible or, if they are perceptible and visible, are often undervalued.

Contemporary arts practices call on us to think anew through remaking the world as we know it. Building on this ethos of practice as thought in the act, I want to suggest that arts practices with people with intellectual disability need to be recognised as crucial to building ecologies of sensation that highlight and respect the experiences of people with intellectual disabilities. This call responds to increased attention being paid to matter and creativity in social sciences and humanities research, often referred to as 'new materialism' (van der Tuin, 2011) or Deleuzian-informed methodologies. Such research practices posit affective, performative, machinic, enfleshed, vital approaches to research in ways that embody and perform ideas developed in Continental philosophy (Whitehead, 1926; Heidegger, 1962; Ahmed, 2008) and, specifically, the work of Deleuze and Guattari (1983 [1972], 1987 [1980], 1994 [1991]). New materialism calls theorists to revisit a Marxist emphasis on materiality in research, just as it calls for an embodied, affective, performative, relational understanding of the research process. So too do theories of practice as research, which show us clearly that the intersection of making and thinking is important.

Rather than thinking through the uniting qualities of debilities, let us better understand the differences marked by disabilities. I want to develop a robust ecology of sensation, bringing feminist new materialist theory together with Carter's (2004) suggestion that 'the language of creative research is related to the goal of material thinking, and both look beyond the making process to the local reinvention of social relations' (p. 10). Here we see the philosophical and social significance of creative practice as political activism laid plain. Echoing Barrett's (2007, p. 1) proposal that 'artistic practice [can] be viewed as the production of knowledge or philosophy in action', I advocate for affective activism developed through making art with intellectually disabled people. We need to build ecologies of sensation that acknowledge, appreciate and respect. The body, and embodied interactions, are pivotal to new materialism, as new materialism calls us to think through complex intra-actions (Barad, 2007) of the social and affective. Embodiment is a complex process of encounters, intra-actions with other bodies and thus a core site for new materialist analysis.

This begins to show why thinking about matter and performative practices matters—if bodies and things are produced together, through performance, then 'things' and how they might act on bodies are co-constitutive of our embodied subjectivity. The concept of intra-action is central to Barad's (2007) new materialism, and refers to the movement generated in an encounter of two or more bodies in a process of becoming different from themselves and each other. In other words, focus shifts from the subject and/or the object to their performative entanglement; the event, the action between (not in-between), is what matters.

As a way of exploring this entanglement and co-constitution of matter and subjectivity, new materialism has emerged as a methodology, a theoretical framework and a political positioning that emphasises the complex materiality of bodies immersed in social relations of power (Dolphijn and van der Tuin, 2012). Matter teaches us through resisting dominant discourses and showing new ways of being. Bodies resist dominant modes of positioning, political acts defy government rule, sexuality exceeds legal frameworks—resistant matter shows us the limits of the world as we know it, and prompts us to shift these limits. This opinion piece is not intended to build a particular argument pertaining to the pedagogical nature of matter, or to simply open debate on what the concept of debility might take away from understandings of disability. Rather, I am looking to develop the concept of ecologies of sensation and affective activism as a way of seeing and feeling the political economy of intellectually disabled lives. The matter, performance and senses of intellectual disability are both pedagogical and resistant.

author biography

Anna Hickey-Moody is the Co-Director of the Disability Research Centre and Head of the Centre for The Arts and Learning at Goldsmiths. Her work focuses on the politics of disability, youth arts practices, gender and cultural geography. She is interested in generating new stories about disadvantaged and disabled youth in ways that do not re-inscribe marginalisation. She is Head of the PhD in Arts and Learning at the Centre for The Arts and Learning, where she leads the research collaborations of an interdisciplinary team of practitioners and researchers. She has developed a philosophically informed cultural studies approach to youth arts as a subcultural form of humanities education. Through developing a concept of small public spheres, her recent book *Youth, Arts and Education* theorises young people's creative practices as a form of civic participation. Her 2009 book *Unimaginable Bodies* creates a Spinozist concept of an open body, an assemblage of affects made through collaborative arts practice that breaks apart dominant medical and social codings of young people with disabilities. She also researches and publishes on masculinity. She is interested in the politics and aesthetics of masculinity read as embodied critique of institutionalised patterns of hegemony. Her 2006 book *Masculinity Beyond the Metropolis* is a global ethnographic study of the lives of young men in 'out of the way' or hard to reach places. The book considers ways in which the everyday lives of these boys are mediated by global scapes of media production and consumption, economic globalisation, generational change, and spatial and temporal configurations of subjectivity. She has edited a number of collected works including an anthology on pedagogy, media and affect called 'Disability Matters', which explores how ideas and experiences of disability come to matter across assemblages of media, through vectors of affect and experiences of pedagogy. Recently she completed an anthology on new materialism, arts practice and cultural resistance, out with Rowman and Littlefield later this year. She is currently completing a book on the politics of educational imaginaries, place and affect with Valerie Harwood and Samantha McMahon.

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