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Storying disability's potential

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ABSTRACT

In this paper, we weave in and out of theory and narrative in order to consider the potential of disability and its relationship to knowledge construction. We consider theories to be stories that one can tell about the world. And these theories are enlivened by other stories that we tell about ourselves and the world around us. As disability researchers, we explore the ways in which disability becomes known in the world and we do so through our own tales and theoretical narratives of knowing disability. In telling stories, then, we break down artificial boundaries between theory and narrative. And in theorising our stories – and storying our theories – we seek to explore the potential of disability to unsettle and challenge exclusionary curriculum. This textual assemblage traverses diverse themes including diagnosis, school programming, welfare, transportation, social interaction and access.

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Introduction

Throughout this paper, we offer a number of musings and narratives on the ways that disability mediates experience (and vice versa) to consider practices, processes and elements of society that have a direct implication on inclusive and exclusionary education. Our purpose is to weave in and out of theory and story in order to consider potentialities of disability to challenge dominant discourses and assumptions of educational programming, curriculum and pedagogy. This potential relates to what Garland Thomson (2005) terms *rethinking*; how we might engage in new ways with and make sense of the social world. This engagement is a very practical one (considering how we go about our lives in a mundane sense) and a theoretical one (the idea that disability might help us to understand the social world as we go about analysing it). As disability researchers, we are keen to explore the ways in which disability becomes known through education and its associated support structures and we do so through our own stories and theoretical entanglements of knowing disability too.

Here we draw on the term 'story' in three simultaneously interrelated ways. First, inspired by Gough's (2004, 2010) performance of imaginative curriculum inquiry, in relating our stories we break down artificial boundaries between theory and narrative; between fiction and fact; between human and non-human; and between being and doing in the

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complexity of enacting inclusive development. For Gough, who coined the term ‘narrative experiment’ (2004, 253), the purpose of writing narrative is ‘to test ideas, to “weigh” them up, to give ... a sense of their worth’ (2010, 50). Gough finds solace in Deleuze and Guattari’s (1987) conceptualisation of rhizomatic thinking in social science inquiry, in particular, the potential of nomadic inter-connections between information, communication, knowledge technologies and posthuman subjectivities (see also Goodley 2007). The conditions of possibility brought about through these entanglements provide useful terrain for the experiment of disability potentialities in education.

The second way in which we evoke the term ‘story’ relates directly to curriculum and pedagogy. Following Grumet’s (1981, 115) definition of curriculum as ‘the collective story we tell our children about our past, our present, and our future’, we are conscious that in standard schooling structures, curriculum has had a restricted interaction with disability in favour of normalised conceptions of personhood (Erevelles 2005). By foregrounding affirmative stories of disability that emphasise the complexity of inclusion under particular conditions, we hope at the same time to generate engagement with curriculum in ways that question limited conceptualisations of inclusive schooling. We call these *curriculum enactments*, and their formation consists of varied engagements with experience, language, memories, theories and ideas. For Pinar and Grumet (1976), autobiographical regathering, projecting, reflecting and rehearsing of learning stories is a useful method of reconceptualising curriculum. At times our shared narrative is rooted to the polity of the school, at others it attends deliberately to public pedagogy – the ‘spaces, sites, and languages of education and learning that exist outside of the walls of the institution of schools’ (Sandlin, Schultz, and Burdick 2010, 1). Our purpose in explicitly drawing attention to these ‘spaces’ is to emphasise the situatedness of curriculum knowledge, the multidimensional non-binary of disability and inclusion, and as well the blurring between fact and fiction in educational inquiry. Returning to Gough (2004, 2010), we are aware that our stories are peppered with details that we deem factual, however, these are only given meaning through the story-telling practices we use to relate them. In Gough’s (2010, 45) terms,

If we think of all stories of educational inquiry as being fictions, we may be less likely to privilege without question those that pretend not to be, and more likely to judge each story on its particular merits in serving worthwhile purposes in education.

Exploring equality and inclusion as a fiction that is labelled as fact in various arenas of experience, we seek to demonstrate how the confines of curriculum might be re-orientated through such a narrative experiment. That our story – the entanglement of our individual stories – at once concerns itself with the historical conditions of our ontologies is an outcome of the sorts of work we hope to encourage among teachers and learners. We will return to this theoretical thread later.

And finally, the third way we deploy stories in this paper is methodologically (as a means to explore questions of disability and education) and analytically (to think about disability and education through the stories that we tell). And this appeal to the embedding of history and culture in the stories we tell is another compelling reason to embrace narratives as they consider disability and other questions of the human (see Goodley, *Forthcoming-b*). Our style of writing for this paper adopts an explicit engagement with story-telling and seeks to lace this with analytical reflections. We do not follow an orthodox empirically structured style of writing (literature-method-analysis) because we want to

sit with the stories we cite and reflect discursively upon the themes that they illuminate. We are guided in our reflections and analysis by a commitment to theories that have emerged from the interdisciplinary field of disability studies (Goodley 2016). Two theoretical themes resonate with us in the writing of this paper. First, disability is often marginalised by curricula. When disability does enter it tends to be treated as a problem. And this marginal positionality can create real problems for people whose identities are in some ways connected with this phenomenon. Second, and more positively in a theoretical sense, disability can be reasserted as a resource for rethinking curricula. Disability offers up new ways of thinking about the self and society; as well as our histories and social positions. But for now let us start with a story from Ben.

An anchoring narrative

It would be absurd to proclaim that my impaired vision does not saturate my subjecthood; that my onto-epistemological position could be even separated from the murky optical vision with which I ‘view’ my surrounds. My diagnosis was, after all, the substance of my coercion into special education (Whitburn 2014); it impacts daily social interactions with known as well as unknown people; it assures that access to physical and digital environments is forever uncertain. Its affordances expedite work access considerations, transportation concessions and tax breaks – the latter coupling not only for me, but also for my ‘carer’, or as I would describe her, my partner. That these seemingly incongruous manifestations can coincide simultaneously might seem unfathomable to many, though to me, they are routine. These are indicators of the precariousness of inclusion for people with disabilities as it is domesticated into the normative social state – the technologically mediated, welfare and rights-based entanglements of disablement. Would I swap it? Give it up if only to ‘see’ again? Not likely. However, the larger normalising processes developed to cultivate inclusive opportunity – special educational provision, disability services and concessions – advance a limited conception of what it means to be inclusive. (Ben)

Ben’s story provides a powerful opener for our explorations. His is an anchoring narrative on which we might build. Indeed, embedded in Ben’s disclosure, are many disability themes including the diagnostic process; physical and digital environments; carers and lovers; technology and transportation; welfare and rights; special and inclusive education. We wonder how often the stories that we ask children to attend to through the curriculum deliberate over the complexity of inclusion – practices, processes and elements of society – in ways that might lead to critical engagement. We suspect that educators do not often elicit nor encourage the telling of complex stories not least because of the performative demands of our neoliberal schools. We use this paper, then, as a deliberately indulgent space to use theory and story together to consider a few of the many ways in which disability speaks to the complexities of educational inclusion and exclusion. That we might consider storytelling an indulgent act in relation to the development of curriculum is itself a sobering observation worth pausing over to think. For now, let us explore further into some stories of disability, education and curriculum.

Diagnostic stories

Disability came into my life in many different ways. Through family. Via educational categories in the schools I attended. In popular culture. I became most aware of diagnosis as a psychology undergraduate. This was a strange time for me. I had fallen in to this choice

of course through luck or misfortune – depending on one's take on the discipline – and as a student I grew to have many major reservations with the workings of psychology. Diagnosis celebrated psychology's discoveries: abnormality, mental illness, disability, impairment, psychopathology, developmental delay and handicap. Psychology marked ontological shortfall and neurological deficit. Diagnosis did not seem to leave a lot of the human intact. (Dan)

If we imagine diagnosis eating away at human wholeness, its appetite seems insatiable. While we are cautious not to merely rehearse the recurrent – yet certainly instructive – concern that disability by default presents a problematic to normative order (Davis 2010; Erevelles 2011; Kleege 1999; Oliver 2009; Titchkosky and Michalko 2009), diagnosis of impairment triggers inestimable capillaried affects for the diagnosed and their families. Their educational and employment futures, their relationalities with each other, with other people, and with technology are all conditional on slippery categories of locality, social class, and race. A recent Senate Report in Australia (Commonwealth of Australia 2016) heard that families of children with varied diagnosed impairments faced diverse educational inequities dependent on where they lived, their financial means, and their cultural backgrounds.

In my own case, diagnosis of a sensory impairment activated a host of aligned encounters for my family and I. Though with British background, at the time my working single mother and I lived in a regional town that was more than an hour by road from the urban centre which housed the 'necessary' remedial services. The medical diagnostic machinery in the capital city – to which we travelled frequently – was adamant that I would require special education attention; a recommendation to which my mothers' resistances seemed ineffective. My early primary education years were a series of trials and tribulations as I would be 'tried out' in first a local mainstream setting, and then placed on a coach to attend a school with a special education unit in the distant urban capital. This experimentation was driven, in the main, by an emerging acknowledgement that neither could class teachers develop inclusive teaching and learning opportunities, and despite my best efforts, nor could I make use of the optical resources of a regular classroom including printed text, diagrams and visual cues. The system resourced with the special technologies of braille tuition and an expanded core curriculum (Hatlen 1996) would subsequently take hold and cling on through the entirety of my schooling. (Ben)

In his analysis of school choice, Ball (2006) finds that working and middle-class families' decisions about the settings they would enrol their children were contingent on a complexity of time and space interactions. While we acknowledge that school choice is a rather new development of market individualism in education policy (Rizvi and Lingard 2010), for parents of children with impairments, these considerations are seemingly ignored in favour of specialist resources. Parents' aspirations for inclusive education take a subordinate role to remedial experimentation (see Ryan and Runswick-Cole 2008). In this sense, then, families with disabled children (or disabled families as Traustadóttir (1991) prefers to frame them) exist on the borderlands of professional decision-making. Once again this highlights that the presence of disability reduces the extent to which families can agentially stake a claim to inclusion in their communities – albeit communities based on choice. However, we are cognisant that as with the participants of Ball's study who lived with less financial resources, extensive options are not a luxury afforded to all. Layers of disadvantage, and we intend for this phrase to mean the way that low socioeconomic status and disability manifest as vehicles for limiting inclusive opportunity, touch many of us in different ways.

While public policy around much of the world is concerned principally with matters of equality – inclusion through access and participation – global priorities of boosting human capital to respond to the knowledge economy is not extended to all (Rizvi and Lingard 2010). As Rizvi and Lingard point out, narrow precepts of equity are evoked in the development of market-driven policy positions of equality, ones of access that as our accounts thus far have demonstrated, fail to broaden conceptualisations of what inclusion might mean to those with diverse ways of working.

Seeking to pinpoint an affirmative outcome from the above narrative develops for me an ambivalence that is itself born out in educational provision across Australia and elsewhere. To some extent, travelling alone on a busy coach more than two hours per day as a five-year-old inculcated a tranquillity – a confidence to interdependently travel amidst strangers I can barely identify. This is a skill I relish: I list travel and adventure as my highest budget expenditures. In addition, it was at this school where I was introduced to Braille. How this system of dots has subsequently mediated my access to literacy, to signage, to an often under-conceptualised material embodiment ought not go unmentioned. Why these outcomes, though, are related either directly or indirectly to deficit and associated thereby to special education is difficult to accept. (Ben)

Both of the authors share a difficult relationship with special education. The very idea of segregating a group of young people from their non-disabled peers – on the basis of an impairment label – seems at best arbitrary and at worse a culturally violent act of division. Segregated schooling keeps some children away from other children and breeds a social attitude of hostility to anything that differs from the norm. At the same time, however, Ben's story signals the need for a nuanced critique of educational experiences particularly when they are located in the life course of an individual. Specialist transport and mediation have skilled up Ben in ways that are fundamentally part of his make up as, for example, traveller and scholar. But Braille and solitary travel to and from school also signify education's typical response to disability: as human difference requiring expert and distinct interventions. These interventions, which comprise a programme of initiations including contingent access to curriculum, are 'reductive, empirically insensitive [and] even morally questionable' (Clough 1998, 327–328). Rather than Braille being a skill set shared by many it remains as an activity only undertaken by people associated with the phenomenon of blindness. Moreover, separate forms of transportation cannot help to breed distinct kinds of understanding of divided groups of human beings.

'Window licker' was a phrase banded about at school. I recall asking a friend what it meant. I was rebuked for not understanding this so obvious-a-phrase and then told; 'you know, it's the MENCAP¹ kids on the yellow buses'. I remember thinking how horrendous, how inhumane a choice of words. But I also recall those yellow mini-buses. I would be waiting with my friends for my own school bus to the local mainstream school. Meanwhile, these mini-buses transported groups of disabled children to schools we knew nothing about, that we would never visit. And these kids remained behind the windows of the bus; never to enter our local communities, our friendship groups, our leisure centres. It was as if they were caught up in a never-ending bus journey from home to specialist school and then on to another 'special' setting. (Dan)

Returning to Grumet's (1981, 115) definition of curriculum as 'the collective story we tell our children about our past, our present, and our future', then it is an imperative that we capture stories of diagnosis and trace their impact on labelling individuals' life chances

and the wider communities in which they appear and disappear. Diagnosis customarily implies the identification of a problem; a definitive point from which future interventions will distance an individual's development. At the same time, diagnosis undoubtedly opens up (or closes down) access to a host of economic, cultural and educational resources (at least in rich income nations with some semblance of a welfare system). Some of these resources are experienced as more empowering than others (Braille wins over segregated transportation). Yet, all disability diagnoses inform the kinds of stories that can be told about disability and the way that disability is represented in curriculum.

Diagnosis and disclosure of disability

As well as with many diagnoses, blindness is a slippery customer whose existence invites ad-hoc responses from those who encounter it, as well as those who live with it. In Georgina Kleege's (1999, 13) terms, 'it's the word *blind* that causes all the problems'. More cultural-linguistic analysis than critical theorisation, Kleege's argument pivots on the ambiguousness of definition understood by many in relation to the category of blindness. At worse, the term invokes an understanding of complete sightlessness. Though as Kleege points out, only a small percentage of card carrying 'legally' blind people live in complete darkness. The rest – and Ben is counted in this group – have varying levels of inexplicable vision that along with a raft of multi-sensory idiosyncrasies, constitute our embodiment.

However powerful, diagnosis seems only ever to provide only some of the answers. It may demarcate the diagnosed from normalcy by declaring unsuccessful prevention, however, its purposeful deliberation on technical rational explanations ensure that the extent to which it might set off a more thoroughgoing and affirmative existence is typically unrealised. In a detailed account of receiving a diagnosis of macular degeneration, Kleege (1999) explains that her 'disorder' (15) was 'defined' (Kleege 1999) by a vision specialist who chose not to engage her and her family with any of the services or technological developments that might affirmatively support her education. She was not encouraged to explore how she might make best use of residual vision, nor how simple technologies such as recorded books might support her learning. Lacking anything but negative stereotypes of blindness upon which to base her emotive response, Kleege writes of shunning any connectivity with its grip:

I did not use the word. I was not blind. Blind people saw nothing, only darkness. *Blind* meant the man in the subway station, standing for hours near the token booth, tin cup in hand, a mangy German shepherd lying on a bit of blanket at his feet. That was not how I saw myself. Surely there was some sort of mistake. Or else it was a lie, and as long as I did not repeat it, refrained from speaking the hateful word and claiming identity with the beggar in the subway, I could keep the lie from becoming a reality. Like Kleege, I have had trouble coming to terms with the embodiment of my impairment. That special education dominated my schooling experience, and that seeking to carve out a career in a vocation of my choosing were contingent on my impairment has been difficult to come to terms with. Disclosure is a line in the sand that I have attempted to agentically traverse, though having learned to engage creatively and theoretically with these concerns, I have come to recognise that I am most comfortable in social contexts when my blindness is on the table. That this must precede me, however, with all of the baggage of blindness described by Kleege, is a troubling hazard. (Ben)

The baggage of blindness that Ben describes is a lovely turn of phrase. We all know someone who has a lot of baggage. If we are honest with ourselves, we all come with baggage. When I think about my own, as it relates to blindness, then two differing thoughts come to mind. First, there is childhood Dan – primary school Dan – when blindness was akin to horror, loss and tragedy. I recall blindness being a common trope in those imported American television series such as *Little House on the Prairie* or *The Waltons*. How awful it would be to be blind. Second, there is university student Dan; newly signed up to the Socialist Worker's Student Society and a keen advocate of the social model of disability. This approach – a working theory developed by disabled people – asked us to sideline impairment (the unit of analysis for most people who consider disability in terms of physiological, cognitive or psychological deficit) and face up to disability (the societal exclusion of people with impairments). The problems of blindness, then, were not individual matters of biological failure but the consequence of a society geared up to serve the sighted. (Dan)

In order to disclose disability then we require someone – or some institution – to receive this information. The problem with these receivers is that they are often already primed and ready to accept only particular kinds of information. Disability is invited to be known in the world only in ways that are already acceptable to that world. One acceptable line of thinking is that blindness is bad. Hence, in order to announce oneself to the world, disability has to be recognised through the lens of a pathologising hegemony. And we use the ocular-centric term lens to emphasise our point: blindness is understood as the absence of sightedness, the lack of awareness, and the deficiency of wholeness. As a counter-hegemonic response, the social model offers the opportunity to reinterrogate the disablist hegemony. One wonders, though, how much the social model has to say about the experience of blindness – or any other impairment for that matter (Whitburn and Michalko, [Forthcoming](#)) – as but one ontological aspect of any given reality.

The phenomenology of disability

Both of the authors are students of the social model of disability. This counter-hegemonic approach resited disability as a social and political concern and made disability studies a space through which to contest disablism and exclusion. In terms of curriculum development – that is to say, the telling of stories about disability and humanity – then the social model provides an incredibly powerful set of resources for comprehending the ways in which disabled people are excluded by everyday cultural practices that have been designed by non-disabled people for non-disabled people. As the work of Erevelles (2005, 2011) has consistently shown: disability tends to be absent from curricula and this erasure haunts our educational institutions. The social model turns up, then, as a powerful antidote to the widespread educational unawareness vis a vis disability. However, while we both acknowledge the power of the social model we do worry also about remaining ignorance even after the social model has had its way with curriculum, pedagogy and education. Our question is this; what does education really know about the experience of disability? For social modellers, such as Mike Oliver (2009), this question would be answered by (i) distinguishing between impairment (the cognitive, sensory or physical difference of an individual) and disability (the consequences of the social exclusion of people with impairments) and then (ii) focusing on disability (which is a public concern) rather than impairment (which is a private and personal matter). So, to use this distinction,

the social model has lots to say about disability and little to offer in relation to impairment. This observation is not a new one and was a strong line of thinking developed by British feminist disability scholars (Crow 1996; Morris 1992; Wendell 1996). And we revisit this potential problem of the social model of disability because we are keen to engage with the experiences of impairment and disability; of how they rub up against each other, acting and inter-acting to constitute ourselves. Dan's blindness baggage explained above has been further beautifully complicated through a chance meeting that Dan had with Rod Michalko and his partner Tanya Titchkosky at the Society for Disability Studies conference in Tucson Arizona in 2009. As Dan recalls:

We quickly bonded over a shared love of beer, the Beatles and storytelling and then, in what seemed like a whirlwind, my partner Rebecca Lawthom and our two kids Ruby and Rosa were sharing holidays with Rod and Tanya. This is when I started to actually learn about blindness. And its hidden referent; sightedness. *Learning* is the key term here. I am not sure if I have *learnt* anything. I do know that with Rod, Tanya, Rebecca, Ruby and Rosa we are learning about blindness amongst other stuff. This other stuff includes the weather in Winnipeg, the Northern Quarter in Manchester, Nottingham Forest Football Club, American baseball, parenting teenage kids, being a teenage kid with parents who are learning to be parents of teenage kids, low salt recipes, pulling out crab meat, Canadian rock n roll, Welsh culture. And blindness. And sightedness. (Goodley, [Forthcoming-a](#))

Over the years Dan, Rod and Tanya have got to know one another and it was during a shared vacation that the following happened.

Driving blind

We are in a Chinese restaurant in a small town in Ontario, Canada (sadly not Winnipeg which we will holiday in one day). The meal has been a success. Ruby and Rosa have eaten their body weight in ice cream, I managed to find the salt n pepper squid, and Rod, Tanya and Rebecca have been enjoyed the Coors Lite © and red wine respectively. I am on the diet coke. It is lunchtime after all. Finished, we stand up as Rod produces his white stick. He quickly unfolds it from its three-section-snap-down-resting-position and releases it like a piece to tap the floor in style. Rod grabs Tanya's arm and they follow me as we leave towards the door. Impatient, as always, I take the lead. The hire car is just outside in the parking lot. Rebecca and the girls are close behind Rod and Tanya. Rod then has a light-bulb moment. Rod pulls to a stop. He happens to be by a busy table of a family of six. He asks, 'Dan, shall I drive?'. I reply. 'Sure, here are the keys'. I throw the keys. They beautifully land and nestle in Rod's right hand. His left hand clutches the white cane. The family of six onlookers nearly drop their chopsticks in shock. (Goodley, [Forthcoming-a](#))

Smiling Irish eyes

In a similar tale involving travel and the perversions of social navigation, three friends and I, flown in from our home city in Australia, were in Galway Ireland, catching up over numerous pints and anecdotes of our respective travels across Europe and elsewhere. Each of the three is well-sighted. I, on the other hand, am known to carry – and to frequently lose – a white cane that I use on occasions that warrant navigational support. When making a night of it, the 'supplement[ary] communication' (French, 1999, p. 23) conveyed through the unfurled aid offers plenty of unspoken detail to fellow pedestrians, to the barkeep and security. Its utility is simultaneously in its aid to traverse the physical as well as social environment, of impairment and disability, and as well, its easy extraction. Emboldened by Guinness to mischief-making on this drizzly afternoon, my friend felt it could well be beneficial that he should use the cane when approaching the door security of a particularly noisy

bar. We're permitted entry, with no more than some cautionary advice to 'Take care of your intoxicated mate' from the doorman gesturing to my friend with the cane. Having entered, located a table and another round of pints, our cheerfulness continued unrestricted, until I felt the infallible urge to visit the toilet. Like on countless prior pub trips, my friend handed me my cane and in his best effort provided a descriptive route map to the bathroom so that I might go alone. At this point we were spotted; I, using the cane with considerably more familiarity to find relief, while my friend ably returned to the bar to replenish our drinks without need of aid. The doorman called us any number of expletives for having successfully played such a seemingly pointless trick. (Ben)

One might read these stories in a multitude of ways. One might be unsettled by the ways in which the family or the pub security man might have been made to feel uncomfortable. Perhaps these jokes are in poor taste. Or maybe, like Rod, Dan, Rosa, Ruby, Tanya and Rebecca you share the joy of playing together with blindness and driving; two incompatible phenomena, insofar that driverless technology is yet to make its way onto our city streets. Or perhaps you are concerned for the way that people who use support devices such as a cane, may not be what they appear. What is clear, and perhaps what we could all agree upon, is that through getting to know one another Rod, Dan, Tanya and the Rs, along with Ben, his friends, and an Irish security guard all get to know a little more about disability, blindness and sightedness (as well as a whole heap of other stuff associated with whom we individually and collectively are).

Similarly, here in this paper, Ben and Dan get to know a little more about one another as human beings and disability studies researchers. Neither should be separate entities. One should not preclude the other! But, interestingly, through the process of writing this paper, Dan and Ben come to understand the lives and theories of one another even better. The phenomenology of disability refers to these relational moments when we encounter one another and the human and non-human entities around us. There is a material quality to these moments (we touch and or touched by our surroundings), an affective imprint in these encounters (we get to feel the world and those around us) and an ontological centrality to these relationalities (we get a subjective sense of oneself and the other). These specificities are missing from the overly structuralist interventions of the social model, and as well mandated curriculum. Though, these moments invite the telling of stories. A current project that Dan is involved in – the Economic and Social Research Council funded Living life to the Fullest – brings together co-researchers of disabled young women with life-limiting and life-threatening impairments. This project has invited a number of opportunities to listen carefully to the relational encounters that disability brings to the world; not least the opportunity to consider the intertwined, knotted and entangled connections that make us human (see Liddiard et al. 2018).

Returning to curriculum enactments

What we have offered in this paper are narrative experiments about the phenomenology of disability, of coming to know the physical and social relationships of impairment and disability through diagnosis, school programming, welfare, transportation, and interdependence on people, technologies, things, and humour. Our interest is the enactment of curriculum – the ways that curriculum is designed, delivered, engaged with and researched

– and how this enactment can come together to constitute what is understood as knowledge. It ‘requires the re-reading of the story lines of inclusion/exclusion’ (Moss and Harvie 2015, 261), which facilitates our direct engagement with the development of knowledge (See also Ware 2001).

In seeking to push work of this kind into curricula enactments, we acknowledge that ‘in the twenty-first century, curriculum should be realised through the hybridity that entangles our world’ (Moss and Harvie 2015, 264). Recognising that it can be inherently ambitious to enact teaching and learning that is accessible to all, Moss and Harvie advocate for cross-disciplinary knowledge synthesis through curriculum design. For them, the central purpose of adaptable education programming is ‘curriculum dispositions’ (268) – pedagogical decision-making driven by constant student, teacher, and school wide-led inquiry, underpinned by knowledge of context. Citing both Letts (2013), who advocates for explicit consideration of which identities are either included or excluded from curriculum materials, as well as Clough (1998), who urges teachers-as-researchers to seek to learn about lived experiences to underpin inclusive curriculum, Moss and Harvie’s framework of cross-curriculum design connects with our narrative experiments about disability potentialities in a number of ways:

- Both and simultaneously as teachers and students, we came to this paper with an agreed question: ‘How might stories about disability potentiality disrupt assumed deficit?’ – we both agreed on the specifics of this inquiry before starting;
- As we shared drafts of our narratives with each other, arranged, re-arranged, and created textual stories that contributed to each other’s locale of experience, we came to know each other in different ways through the languages we used and the experiences we shared. These were conversational engagements; through which we came to learn about different angles of disability potentiality;
- We came to recognise the cross-disciplinary disposition of this work from the beginning, as these experiences ducked and weaved formal institutions, as well as moments of diversion.

Let us expand on these points. The stories we have shared deliberately attend to what Hughes (2015, 80) calls the ‘history of pathologization and supervision’. However, they do so in ways that are as much concerned with our own embodiment and meaning-making of socio-cultural circumnavigation, as they are with the impositions of the external and globalised world. Our purpose in presenting these experiments is to highlight nuances of understanding as we create and co-create them. And our intention is that the creation of narrative, as an experiment of fictions, is a valuable way of learning. Take, for example, how Dan wrote of coming to know blindness, and how we have both purposefully deployed language from the start that seeks not to engage with a fixed ontological position of ‘being’ disabled, or ‘being’ a student of special education. As researchers engaged with disability studies, this is our active struggle against the delegitimation of uncomplimentary knowledge about impairment and disability. You might also have noticed that both of our narrations of coming to know blind driving, and drinking, contain different characterisations, introduced variously as being sighted, blind, or neither depending on our own positioning and taken-for-granted assumptions about

ourselves and the world around us. We are not convinced that there is anything wrong with that, though the contrast provided says much about how we assume the world. If we had the space, further inquiry might explore the histories of our dispositions that lead us to these epistemologies.

Conclusion–potentialing subjugated knowledge

In this paper, we have offered a way that we consider beneficial to orientating curriculum enactment towards affirmative engagement with disability. Through the development of narrative, we have generated what Foucault (1980, 82) calls subjugated knowledges – ‘blocs of historical knowledge which were present but disguised within the body of functionalist and systematising theory’, to which we would add policy, curriculum and practice. To conclude this paper, it seems appropriate to turn our attention to how others involved in education – teachers, students, families, leaders – might enact curriculum along similar means. Like for Moss and Harvie (2015), who urge ‘the academic discourses of curriculum, in everyday curriculum talk and actions in schools and classrooms’ (263) to develop inclusive opportunity, we hope too that the methodology we have demonstrated here might be put to work to engage systemically with any number of diverse ontologies, epistemologies, and shared experiences in the creation of knowledge. Drawing on Gough’s (2004, 2010) performance of imaginative inquiry through narrative experiments, we have shared a number of musings intended to demonstrate how we might rethink disability (Garland Thomson 2005). These are serious – and at times playful – explorations of the historical conditions of our ontologies.

We recognise that across compulsory schooling, curriculum is, in the main, mandated by state or national systems of education driven to achieve high standardised outcomes. At the same time, the curriculum is often a point of departure from which students with disabilities are channelled into special education programmes (Moss and Harvie 2015). It might be understood in these circumstances that the rigidity of mandated curriculum, wherein students with divergent accessibility requirements such as augmented and alternative communication (AAC) devices, text creation (rather than writing) using audio and visual resources, are not facilitated access to curriculum. Similarly, students from particular cultural backgrounds such as indigenous populations of Australia consistently achieve low literacy outcomes in accordance with mandated curriculum, because of limited conceptualisations of literacy practice in policy (Auld, Snyder, and Henderson 2012).

In spite of the ubiquity of imposed restriction to curriculum, however, it is feasible for curriculum actors to carve out moments of social practice in their work. Aukerman and Chambers Schuldt (2017) have demonstrated that dialogic pedagogy can be a useful way of ‘bucking the authoritative script of a mandated curriculum’ (1) so as to provide access to diverse learners. The point we are making is that experiments of the kind we offer in this paper to the enactment of curriculum, at any position of the curricula system – between teachers and students, school administrators and teachers, researchers and policy-makers, and so forth – might be put to work to explore any number of subjugated knowledges through experience. However, and as Aukerman and Chambers Schuldt have shown, an experiment with curriculum does not need to be only textual, but rather

responsive to the context of the diverse ontologies of its configuration. We recognise that our own use of narrative has an inherent bias: it is written, and it is about potentialities of disability, leading us to a phenomenology of disability. Albeit a narrow application of inquiry, it is but one way of developing curriculum enactment about subjugated knowledge. And this is simply one example of application.

Note

1. MENCAP is a British charity originally set up by family members of people with learning disabilities. Today MENCAP states that it is a UK charity for people with a learning disability. We support their families and carers, too (<https://www.mencap.org.uk/>).

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References

- Aukerman, M., and L. Chambers Schuldt. 2017. "Bucking the Authoritative Script of a Mandated Curriculum." *Curriculum Inquiry* 47: 411–437. iFirst publication. doi:10.1080/03626784.2017.1368353.
- Auld, G., A. Snyder, and M. Henderson. 2012. "Using Mobile Phones as Placed Resources for Literacy Learning in a Remote Indigenous Community in Australia." *Language and Education* 26 (4): 279–296.
- Ball, S. J. 2006. *Education Policy and Social Class: The Selected Works of Stephen J. Ball*. London: Routledge.
- Clough, P. 1998. "Bridging 'Mainstream' and 'Special Education': A Curriculum Problem." *Journal of Curriculum Studies* 20 (4): 327–338.
- Commonwealth of Australia. 2016. *The Senate Education and Employment References Committee Report: Access to Real Learning: The Impact of Policy, Funding and Culture on Students with Disability*. Canberra: Printer.

- Crow, L. 1996. "Including All of Our Lives: Renewing the Social Model of Disability." In *Exploring the Divide*, edited by C. Barnes and G. Mercer, 55–72. Leeds: The Disability Press.
- Davis, L. J., ed. 2010. *The Disability Studies Reader*. 3rd ed. New York: Routledge.
- Deleuze, G., and F. Guattari. 1987. *A Thousand Plateaus: Capitalism and Schizophrenia*. Translated by B. Massumi. Minneapolis: University of Minnesota Press.
- Erevelles, N. 2005. "Understanding Curriculum as Normalizing Text: Disability Studies Meet Curriculum Theory." *Journal of Curriculum Studies* 37 (4): 421–439.
- Erevelles, N. 2011. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan.
- Foucault, M. 1980. "Two Lectures." In *Power/Knowledge: Selected Interviews and Other Writings 1972–1977*, edited by C. Gordon, 78–108. Oxford: The Harvester Press.
- Garland Thomson, R. 2005. "Feminist Disability Studies." *Signs: Journal of Women in Culture and Society* 30 (2): 1557–1587.
- Goodley, D. 2007. "Towards Socially Just Pedagogies: Deleuzoguattarian Critical Disability Studies." *International Journal of Inclusive Education* 11 (3): 317–334.
- Goodley, D. 2016. *Disability Studies: An Interdisciplinary Introduction*. London: Sage.
- Goodley, D. Forthcoming-a. "Disability Studies & Human Encounters." In *Disability Studies: A Reader*, edited by A. Ghai. Delhi: Sage.
- Goodley, D. Forthcoming-b. *Disability and Other Human Questions*. London: Emerald.
- Gough, N. 2004. "RhizomANTically Becoming-cyborg: Performing Posthuman Pedagogies." *Educational Philosophy and Theory* 36 (3): 253–265.
- Gough, N. 2010. "Performing Imaginative Inquiry: Narrative Experiments and Rhizosemiotic Play." In *Imagination in Educational Theory and Practice: A Many-sided Vision*, edited by T. W. Nielsen, R. Fitzgerald, and M. Fettes, 42–60. Newcastle upon Tyne: Cambridge Scholars.
- Grumet, M. R. 1981. "Restitution and Reconstruction of Educational Experience: An Autobiographical Method for Curriculum Theory." In *Rethinking Curriculum Studies: A Radical Approach*, edited by M. Lawn and L. Barton, 115–130. London: Croom Helm.
- Hatlen, P. 1996. "The Core Curriculum for Blind and Visually Impaired Students, Including Those with Additional Disabilities." *RE: View* 28: 25–32.
- Hughes, B. 2015. "What Can a Foucauldian Analysis Contribute to Disability Theory?" In *Foucault and the Government of Disability*. Enlarged and Revised ed, edited by S. Tremain, 78–92. Ann Arbor: University of Michigan Press.
- Kleege, G. 1999. *Sight Unseen*. New Haven, CT: Yale University Press.
- Letts, W. 2013. "The Curriculum." In *Teaching: Making a Difference*. 2nd ed., edited by R. Churchill, P. Ferguson, S. Godinho, N. Johnson, A. Keddie, W. Letts, and M. Vick, 184–207. Milton: Wiley Publishing.
- Liddiard, K., K. Runswick-Cole, D. Goodley, S. Whitney, E. Vogelmann, and L. Watts. 2018. "I Was Excited by the Idea of a Project that Focuses on Those Unasked Questions' Co-producing Disability Research with Disabled Young People." *Children & Society*.
- Morris, J. 1992. "Personal and Political: A Feminist Perspective on Researching Physical Disability." *Disability, Handicap and Society* 7 (2): 157–166.
- Moss, J., and K. Harvie. 2015. "Cross-curriculum Design: Enacting Inclusive Pedagogy and Curriculum." In *Inclusive Pedagogy Across the Curriculum*, edited by J. M. Deppeler, T. Loreman, R. Smith, and L. Florian, 459–480. Bingley: Emerald Group.
- Oliver, M. 2009. *Understanding Disability: From Theory to Practice*. 2nd ed. London: Palgrave Macmillan Press.
- Pinar, W. F., and M. R. Grumet. 1976. *Toward a Poor Curriculum*. Dubuque, IA: Kendall/Hunt Publishing.
- Rizvi, F., and B. Lingard. 2010. *Globalizing Education Policy*. London: Routledge.
- Ryan, S., and K. Runswick-Cole. 2008. "Repositioning Mothers: Mothers, Disabled Children and Disability Studies." *Disability & Society* 23 (3): 199–210.
- Sandlin, J. A., B. D. Schultz, and J. Burdick. 2010. "Understanding, Mapping, and Exploring the Terrain of Public Pedagogy." In *Handbook of Public Pedagogy: Education and Learning*

- Beyond Schooling*, edited by J. A. Sandlin, B. D. Schultz, and J. Burdick, 1–6. New York: Routledge.
- Titchkosky, T., and R. Michalko. 2009. “Introduction.” In *Rethinking Normalcy: A Disability Studies Reader*, edited by T. Titchkosky and R. Michalko, 1–14. Toronto: Canadian Scholars’ Press.
- Traustadóttir, R. 1991. “Mothers Who Care: Gender, Disability and Family Life.” *Journal of Family Issues* 12 (2): 211–228.
- Ware, L. 2001. “Writing, Identity, and the Other: Dare We Do Disability Studies?” *Journal of Teacher Education* 52 (2): 107–123.
- Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.
- Whitburn, B. 2014. “The Indelible Ink of the Special Stamp: An Insider’s Research Essay on Imprints and Erasures.” *Disability and Society* 29 (4): 624–637.
- Whitburn, B., and R. Michalko. **Forthcoming**. “Blindness/Sightedness: Disability Studies and the Defiance of Di-vision.” In *Routledge Handbook of Disability Studies*. 2nd ed., edited by N. Watson and S. Vehmas. London: Routledge.