

Lives Worthy of Life: The Everyday Resistance of Disabled People

Nick Hodge

‘Spoiler alert’: This article speaks to that of Dr. John Williamson that is published in this year's issue. I have made some effort to avoid revealing too much of the “plot” but those of you who prefer to enjoy the mystery of the disappearing/appearing slow learner as it is intended to unfold are advised to read Williamson's article before this one.

I first encountered Williamson's work in the form of a PhD thesis. I was captivated first by the concept, the originality of presenting research in the form of a detective novel. Next by the beautiful artwork of Emma Williamson that adorns the cover and then once I began to read, as with every gripping thriller, I could not put it down. This work challenges fundamentally the expected form of the traditional social science thesis that nearly always starts with a context chapter followed by a review of the literature that gives rise to the research questions and then the methodology chapter and so on. All that I anticipated did not at first appear in this thesis and yet of course I then came to realise that it had been there all along: it had disappeared and then appeared again. Lopez and Willis (2004) called for researchers to be more explicit about their methodology to set out the philosophy and principles that inform and guide the study. Max Hunter is a bruised and cynical private detective who is in constant dialogue with himself and his client, Williamson, the slightly worn down by the system but “hanging on in there” teacher. This creation of the detective is an inspired artifice. The discussions between the two characters allow Williamson to lay out in detail before the reader every element of the research journey. We share each frustration and each wonder of discovery that happens within the research. In Max, is embodied the very physicality of what it means to conduct a PhD enquiry: the anxiety, the late nights sustained only by coffee, the trials of accessing participants, the compulsion to keep going no matter what, trying to appear like you know what you are doing when you have no idea where to go next, the confusion and uncertainty and the wondering whether any of it will ever come to

Corresponding Author:

Nick Hodge, EdD

Email: n.s.hodge@shu.ac.uk

mean anything.

Presenting research in the form of a novel reminds the reader that all reports on enquiry are constructed stories that are created and managed by the researcher. Kvale (1996) argued that the job of the researcher is to make clear the links between the claims made and the evidence base that support them. Then each reader must decide upon the reliability of research and evaluate to what extent he/she can recognise his/her own experience within it. I was a teacher in special education for many years before working at a University. For me, this research feels “real.” I recognise the teachers and the pupils who are “interviewed” by Max and I can picture the spaces in which these meetings occur. The issues raised by staff and pupils are the ones that troubled me then in my practice as a teacher and continue to do so today. The work is made authentic for me through the level of detail provided, the reflections on the research journey expressed by Max and Williamson and I am convinced by the human but ethical natures of their characters as portrayed within the text. Williamson is a very talented writer who is as at home constructing a novel as he is with more standard styles of academic writing. So this form of thesis would not work for every researcher but it has certainly highlighted for me the potential and value of thinking about ways of conducting and presenting research differently. This text encourages us to be creative and brave but above all reminds us of the need to be consistent, disciplined, and exact. In spite of not having specialist training nor undertaken a lengthy academic course Max comes quickly to understand disability, something that some of those in education with many years of experience never seem to achieve. Max is a “sucker for the underdogs” (p. 49), a Freirean hero who is prepared to put himself at the disposal of others to expose the oppressive practices of the system (Freire, 1970). Max moves amongst those who have been expelled to the margins of society, constructed as non-producers, economic burdens on the capitalist state who are there and yet do not appear (Sassen, 2014). Max might not yet know about disability theory but he knows people. As a detective he researches the lived experiences of others. Max listens and he considers. In the section of the story that Williamson presents here, he sends in Derrida and Foucault to help Max with understanding how the category of slow learner might have come to be formed and the role that the label serves in the regulation and limitation of children and young people. Derrida and Foucault take Max to the “Classification of Disability Research Institute,” a private museum of disability history. So skilled is Williamson as a writer that upon first reading about this museum I immediately tried to locate it on the internet in the hope that I could one day visit. It seemed to contain such important exhibits. Immersed in the story, I ignored the clues that Williamson provided to remind me that “everything is dangerous” (Foucault, 1991, p. 343) and that we all need to remember to “watch our watching, to read our readings” (Titchkosky, 2007, p. 3) as all may not be what at first it seems. The presence of Derrida and Foucault as Max’s escorts around the exhibition or even the fictional nature of Max himself perhaps should have warned me that there might not actually be a museum for me to visit but caught up in the drama I had let down my guard. When I realised my error the museum temporarily disappeared for me only to reappear in the form of all the research texts that have chartered the history of disability and which Williamson has so thoroughly analysed.

Through the tour of the institute Max comes to know the shocking and shameful history of disability. Through photographs, personal accounts and “official” documentation Max observes the systematic denial of the humanity of disabled people, dehumanisation through acts which mark out those who perpetrate them as well as those who suffer (Freire, 1970). Max learns that

diagnosis, categorisation, and labelling “violently mark” and disable children and young people (Goodley & Runswick-Cole, 2016, p. 1): labels are not the benevolent tools designed to support children and young people that many families and practitioners imagine them to be. Instead they are revealed here as tools of the privileged within the capitalist state in order to contain (at best) and eradicate (at worst) those who are categorised as economic burdens on the state and polluters of the workforce (Hodge, 2016). Max witnesses how throughout history disabled people have been and are positioned as other and lesser. Only the bodies that are capable of labour are deemed to have value; “not all bodies are equal, some matter more than others: some are, quite frankly, disposable” (Braidotti, 2011, p. 216). Disabled people are first cast as unfeeling “idiots (who) are insensitive to pain or temperature” (Sward, 1917, p. 498) and then transmogrified into animals (Williamson, 2016). Zoomorphism serves to allow the maltreatment and expulsion of disabled people. Animals can be dangerous beasts that need to be corralled and controlled and even destroyed if they do not earn their right to life or threaten the profit of a healthy gene pool. Once disabled people are made animal, then the Aktion T4 programme of Nazi Germany becomes possible. As Max comes to learn, over 200,000 disabled children and adults were murdered through this programme in Germany alone (Seeman, 2005). Stripped of their humanity these beasts and burdens were viewed by the Nazis as “lives unworthy of life” (Glass, 1999). Max learns of these terrible accounts whilst in a museum. But euthanasia and eugenics have not yet been assigned to history. There is currently in development a fetal test for Down syndrome that demonstrates the potential to be less intrusive and risky for pregnant women and their fetuses (Gander, 2016). This was announced recently in the UK media with almost no challenge or protest even though the implications of the announcement are clear: more women are likely to access the test and more “lives unworthy of life” will be terminated.

The conceptualisation of disabled people as beast and burden is equally persistent. This can be seen in the relentless vilification of disabled people in the United Kingdom media as “shirkers and scroungers” (Garthwaite, 2011, p. 369). A further example is the television documentary that presents Dr. Temple Grandin, a highly respected academic who happens to identify with the label of autism, as “The Woman Who Thinks Like a Cow” (BBC, 2006). As cattle are subject to inhumane forms of control such as electric prods to direct their movements, it is unsurprising that disabled children have been subject to the same practices as “tools” of learning (Silberman, 2015).

For Max, the horrors to which he bears witness become unbearable and he feels compelled to leave the museum. The exhibits are brutal reminders of the devastating effects that the operation of power can have on lives made vulnerable. But within the history of disability can also be found hope and so the museum needs one more exhibit: the everyday resistance of disabled people. Kitchin (1998, p. 353) defined resistance as “the opposition of power: the oppressed fighting back against the injustices imposed by their oppressors.” In the history of disability, Kitchin recorded that such was the dominance of ableist ideology that by necessity acts of resistance by disabled people were for many years individual:

Actions range from living the lives they want, getting an education and a job, to having children, not hiding their ‘deformities’, rejecting ‘normalising’ treatment, battling against stereotypes and prejudice, and seeking to get ‘able-bodied’ people to accept them as they are... (p. 353)

Ryerson University hosts a virtual museum of disability activism and resistance. One exhibit captures examples of disability resistance in the stories of Mathilda, Audrey, and May. These three women were committed to the Toronto Hospital for the Insane at the beginning of the 20th Century and they remained there for most of their lives. Without pay, they were compelled to work and it is estimated that between them they provided the state with 285000 hours of labour. Effectively free “workhorses,” these women refused to be defined by their assigned status. Instead, Mathilda presented herself as an employee of the Institute and asserted authority over her working space. May would wander the grounds of the institute in the early morning in spite of regulations that forbade it. Women like these three resisted their oppression through pride in their work, forming communities and quiet subversion of oppressive regulations (Stackhouse, n.d.). McDonald, Keys, and Balcazar (2007), in more recent research with young disabled people, identified how they resist pejorative and disempowering cultural representations of disability. These include removing oneself from a negative environment and being selective about the spaces one inhabits. Young people assert their authority to decide for themselves their identity and value regardless of how others appear to perceive them. They remind themselves of their worth through acts of positive thinking and turn potentially disempowering narratives into “prove them wrong” motivators that drive them on to achieve. Other forms of resistance include fighting back verbally when encountering disabling attitudes from others and openly celebrating and highlighting one's “difference” (Loja et al., 2013). In Williamson's research (2016), acts of resistance can be seen in Colleen Birdseye's transcendence of her label (p. 3), the quiet but persistent challenge of the young man in asserting that his qualifications were of the required standard to register for an apprenticeship (pp. 4-5), Arturo's rejection of his assigned category and status (pp. 19-22) and the illustrations by the students of their talents in dance, sport, and juggling (p. 23).

In the latter half of the 20th Century, as part of a wider Civil Rights Movement in some countries individual acts of resistance by disabled people developed into collective action (Kitchin, 1998; Köbsell, 2006; Lord, 2010). In the UK in the 1970s, disabled people led the development of a new model of conceptualising and responding to ableist oppression: “The Social Model of Disability” (Oliver, 1996). This shifted the focus of disability away from individual impairment and on to the societal structures that impede the aspirations of people with impairments (Goodley, 2011; Mallett & Runswick-Cole, 2014). Disabled people asserted new rights to decision making and placed themselves in positions of leadership within the organisations that represented them or started new groups of their own (Leach, 1996). Resistance to disability became more visible and demanded the attention of the world (Köbsell, 2006).

The exhibitions at the “Classification of Disability Research Institute” convey therefore the horror and shame of the dehumanisation of disabled people that has led to expulsion, confinement, and attempts at systematic eradication. What it does not capture is resistance and hope - - the refusal to submit to oppression by disabled people who assert their humanity within their everyday lives. Williamson's research and writing and his work as a teacher are also acts of resistance. Like his hero Max, Williamson “doggedly” refuses to allow the slow learner to be expelled to the margins and made to disappear. Instead Williamson supports those labelled slow learners with telling their stories and thereby making known and validating their aspirations and the barriers that thwart them. Disabled people and their allies continue to find new ways of

challenging the insidious and omnipresent specters of Ableism and Normalcy. The digital age, for example, has provided a variety of creative platforms to capture and promote the lived experience of disabled people and represent the diversity and richness of these lives worthy of life (Rice et al., 2015). In the UK, disabled performance artist Liz Crow drew attention to the crime of Aktion T4 by sitting in a wheelchair, dressed as a Nazi, on a plinth high above the crowds in London's Trafalgar Square (Disability Arts Online, 2009). The continued attacks on disabled people by neoliberal-ableist governments that rob them of their incomes and deny them access to independent living mean that once again disabled people are corralled into large scale segregated living (Goodley, Lawthom, & Runswick-Cole, 2014; Gradwell, 2015). All cities and towns require a history of disability museum that would record and display the shame of such practices, both past and current, but also celebrate the heroism of disabled people in resisting them. These museums would act as beacons of remembrance and a warning that we must all “watch our watching (and) read our readings” because “everything is dangerous.”

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