Ableism in Academia

Brown, Nicole, Leigh, Jennifer

Published by University College London

Brown, Nicole and Jennifer Leigh.
Ableism in Academia: Theorising experiences of disabilities and chronic illnesses in higher education.

Project MUSE. muse.jhu.edu/book/81862.

For additional information about this book
https://muse.jhu.edu/book/81862
Internalised ableism: Of the political and the personal

Jennifer Leigh and Nicole Brown

In the popular imagination academia is perceived as a privileged working environment, with high-status occupations, long holidays, and little pressure and accountability. Yet this is not how academics describe the work they do and the environment they work in. Academics are bound by personal values and social norms, which they internalise through their moral commitment to the academy (Scott 1971). Therefore academic identity, working in academia and the specific characteristics and personality traits of academics can be seen as manifestations of internalisation processes (Parsons 1970/1964). The role of work in relation to identity is well documented (Wrzesniewski and Dutton 2001; Witt et al. 2002; Kirpal 2004a; 2004b; Walsh and Gordon 2008; Haslam et al. 2000). Work is not merely a means to be productive, it also influences and moulds us, so that we find our selves in and through work (Gini 1998). Within the context of higher education, work identity and the interrelationship between work and identity are commonly explored in the context of professional identity (Trede et al. 2012) or in terms of belonging to a community (Smith et al. 2010; Billett and Somerville 2004). Becoming or being academic in contemporary higher education is an active process of reconciling, or indeed refusing to reconcile, autonomy, authenticity and values with the success criteria audit of the neoliberal university (Archer 2008a; 2008b; Henkel 2005).
The personal, private

Our argument in this chapter is that the political and personal intersect in a mutually interconnected relationship so that the political impacts the personal, that the public influences the private and vice versa, and that these tensions are played out within the body. Therefore, taking a stand as a disabled or chronically ill academic is a political as well as a personal act and can have physical consequences. Exploring lived experiences as a basis for understanding the social has a long tradition (Van Manen 1990; Ellis and Flaherty 1992). Personal stories and narratives, autobiographies and autoethnographies are perhaps less commonly accepted as a ‘scientific’ method and sometimes dismissed as too narcissistic or self-centred (Holt 2003; Salzman 2002; Sparkes 2002). And yet, if employed systematically and rigorously, the personal narratives (auto) within autoethnographies are merely a starting point for the analytical research (graphy) on culture (ethno) (Ellis and Bochner 2000). In other words, the emphasis on the self is not a narcissistic or self-indulgent fixation: it is a lens through which the social is explored in order to provide better understanding of cultural phenomena. The personal stories are therefore necessary in order to provide the context for socio-cultural interpretations. With this in mind, the following section offers confessional-emotive writing (Chang 2016, 145ff.), which will allow us to contextualise the concerns of being ill in the current climate of neoliberal academia. These extracts draw from a reflective journal of an academic written in the years after becoming chronically ill.

Coming to terms, 2015

So I’m feeling very emotional. The ramifications and consequences of being ill seem to be looming larger than ever.

It feels like I am having to prove myself three times over to make up for being ill. As though I am being punished for being ill. As though living it is not enough.

What’s the line between bullying/discrimination? Being treated differently? Made to feel as though I wanted to be ill?
They call it ‘brain fog’ – for me it was a complete inability to process. I could hear but not understand what people were saying. I was disorientated, confused. This made me anxious.

It was only when I began to feel better – when I started on the correct medication – that I realised that not only was my brain fogged, but my body also.

My research is about embodiment, about being in the body, and not only could I not think, but I could not feel into my own body. Moving was painful. Exhausting. Where once it had been a source of energy.

The invisible illness/disability aspect of this is so pertinent too. Am I protected? Who protects me? I am fighting to do my job to live my life and every thought is a struggle. But other people can’t see it. I don’t feel like ‘me’.

But they don’t know who ‘me’ is. They assume/think I don’t know what. I’m slacking? I want to be like this? It’s an excuse? That I’m trying to get out of teaching to do research?

I was told to concentrate on what I could do – research, writing. I could do this – slowly. But not creatively. No original thoughts. Yet when I did this it was seen as an easy option?

I remember applying for conferences – but it was vetoed because it would upset the team if I went to a conference when I wasn’t teaching.

Complete lack of understanding.

Thing is, it’s only now, when I am feeling so much more like myself, that I can conceptualise it and write, more, express what it was.

But I’m not in it any more.

That said, I’m not yet out of it either.

Am I disabled?
I have a disabling condition.

Where does that sit with a marginalised status?

Or not?

It is hard to have a voice if my mind is not processing my body isn’t working.

I need to move tomorrow to prepare.

To protect.

Am I subject to more scrutiny than my peers? It feels that way.

New normal, 2016

I used to feel an expert in my own body and my ability to read others. Now I don’t. This brain/body fog that inhabits and pains me obscures my sense of myself and my confidence is shaken when it comes to anyone else. I don’t inhabit or represent what I believe and I feel I ‘should’. How can I help anyone else or educate them when they only have to look at me to see how I am lacking?

This inability/unwillingness to accept how I am as a new normal does seem to be driven by the need to produce, to drive around, when in fact in my body I am crying out to do nothing but rest and breathe and heal. I need to heal so much. Then I resent this academy that keeps pushing me to injure myself. I feel broken but I don’t know if they can see or if they care.

Broken academy, 2017

I want to acknowledge the structural issues such as overwork or casualisation that are endemic in the academy. Recently I found myself delivering a session to postgraduate research students at my university on ‘balancing research, teaching and life’. I was struck by the irony of this, as my co-facilitator and I had been exchanging emails about the session at 11 pm and 5 am in the previous days, and I arrived for the session itself hot and out of breath, having run from nursery drop-off to meeting after meeting to get there. How
can we preach the need for wellbeing when we model anything but? When we are driven to do anything but? Is this an environment I would want my daughter to be in? I’d want her to have her eyes wide open. Why do I think of it as a win when a PhD student tells me that they are looking for a career outside academia?

Being perfect, 2019

Today I taught for 5 hours. I was in a room full of people who needed and expected me to show them how to teach, while also expecting the day to be a waste of time, and not wanting to be there. I sometimes feel like I am a performing monkey. I have to be upbeat, I have to have energy, I have to be engaged, I have to be good. I have to be the teacher they dream of being. I have to deliver the right message. Teaching is fun. Teaching is worthwhile. Last week I was teaching a different full-day course and I was so aware of the cost it had on me. I hadn't been practising, I didn't feel strong in my body and I was hyper-aware of how hard it was even to stand. My pores were tired, I wasn't able to hold the energy in the room without leaning or sitting, and yet the room layout was such that I couldn't sit and be seen by everyone. When I would normally perch on a table the table tipped up. I wasn't on my own. I don't think anyone else ‘noticed’ and the feedback we had was good. But I knew that to get through this week and next, teaching for five hours at a stretch day after day, I needed to be more in my body. This means that for the last four days I have got up at 6 am to practise, to be more in my body, to feel whether today I am stiff (always) or off balance, or where I need to be gentle with myself. And yet I end today with iron behind my eyes clamping them down because I know that I can’t rest and recover and recuperate ready for tomorrow, instead I have to sit and write and think and be creative because this manuscript is due in. I cannot take the time I need and it is costing me. My teeth hurt, I am so tired. I don’t have it in me to put in the hours in the evening, at the weekend, that I need to do to get it all done. Others would. Others do. But I can’t. I am only one day into this teaching load. The pressure is relentless. And still, in the classes, I am continually putting in more content, asking my students, my would-be teachers, to consider the needs of their students, to consider their own needs as teachers, to be aware of the pressures of overwork and hyper-productivity. I asked them to think about what it means to be a good teacher, while modelling
being one, engaging with them, conducting the class, as one said, as an adaptive stand-up comedian. She didn't mean that I had a comedy routine, but that I had to adapt and change what I did to fit the needs of the room. Which is what a good teacher does. But a good teacher doesn't flake out or fade out when her students are talking. I did. A good teacher isn't counting the minutes until the class ends so she can get on with something else, something that counts more. I did. And should a good teacher be a role model? I think so. But I did not tell them my story even after a conversation around disclosing aspects of your identity as a teacher and acting as a role model. At the end of the day we talked about the things every teacher should know. I said ‘don’t be a dick’. It covers a lot. And they said ‘a shitty session doesn’t mean you’re a shitty teacher’. I feel shitty right now, what does that count for?

Seen from the outside, 2019

Good job on handling the late student and demonstrating professionalism.

I expected to fall asleep in 5 minutes but it was very interesting.

Really well-led talk, managed to keep attention for a long period of time.

I loved the fact that you refer to what you did earlier in the workshop as an example of group management.

I really enjoyed this ... Pace of the lesson was great and was an excellent example of the kind of teaching I’d like to do.

Neoliberal academia as a workplace

Within the context of the neoliberal academy, overwork and being a high achiever are valued. Academics are high achievers and have matching expectations of themselves. Such ways of working are not inclusive to those of us who are unable or unwilling to work at this level or pace. Female academics particularly seem to make sacrifices for their work, and fatigue, burnout and ill health seem common (Currie et al. 2000; Gore 1999; Kolodny 1998). Through having high expectations, it is
possible for academics to strive for more knowledge, produce better research articles and contribute to the academic community, and thus to feel validated in their identity and their work. However, the line between having high expectations or setting high standards and being a perfectionist is thin.

Models of perfectionism are diverse. Following the traditions of Freud, for example, researchers see perfectionism as a uniform and unitary concept so that a person is or is not a perfectionist. A second school of thought revolves around Hamachek’s (1978) understanding of perfectionism as multidimensional and multifarious. The discrepancy here lies within the disciplinary views of perfectionism as clinical and a stable trait versus seeing it as fluid and changeable. By interpreting perfectionism as multifarious and multidimensional, Hamachek made it possible to hone in on particular elements, such as frequency of perfectionist thoughts or domain specificism (i.e. people may be perfectionists in one area of their lives and not in others: Matte and Lafontaine 2012). This allows for deeper engagement with specific elements and components of perfectionism, which in turn helps forge and understand definitions of the concept. Generally, perfectionism is understood as setting and pursuing unsuitably high and unreasonable standards along with a disproportionate focus on achieving these unfeasible standards and self-evaluation that is overcritical (Frost et al. 1990). This definition forms the basis of the current biopsychosocial understanding of perfectionism, which combines perfectionist strivings with perfectionist concerns and other-oriented perfectionism:

PS [perfectionist strivings] refers to the propensity to set excessively high personal standards that are often unrealistic in nature and to demand nothing less than perfection from the self. […] PC [perfectionist concerns] includes extraordinarily critical appraisals of one’s own behaviour, chronic harsh self-scrutiny, excessive preoccupations with others’ evaluations, expectations and criticism, and an inability to gain satisfaction even when one is successful in an endeavor. […] OOP [other-oriented perfectionism] measures the extent to which individuals rigidly demand perfection from others in an exacting and entitled way and are being highly critical of others. (Sirois and Molnar 2016, 8–9)

Within academia, conversations relating to imposter syndrome, overwork and workaholism (Fassel 2000) emphasise an unhealthy openness towards having high expectations, being pedantic and potentially
having low self-esteem because the high standards set are not met. In this context, perfectionism and perfectionist traits might be the prime determinant for being successful in academia, and they are generally seen as a positive characteristic. Existing research into perfectionism in connection with health and wellbeing highlights that such perfectionist traits play a significant role in psychological disorders (e.g. Flett and Hewitt 2002; Frost and DiBartolo 2002) and thus impact wellbeing (e.g. Bieling et al. 2004; Stoeber and Otto 2006).

The body in academia

There is little space for the body within neoliberal academia. While interest in embodiment within higher education is growing (see for example Leigh 2019a), the push towards managerialism and productivity means that working environments in universities have been described as being devoid of emotional and physical presence (Bloch 2012). The cerebral rather than the physical, emotional or sensory aspects of learning, teaching and research are often privileged. Emotion work is becoming more visible (see for example Brown and Collins 2018). However, traditional teaching spaces and practices are the norm in most higher education institutions due to constraints on resources and space. One of the consequences of this is the perceived impact on the wellbeing of those within universities – both staff and students are reporting more instances of mental health problems and disability (Gill 2010). This often results in an institutional emphasis on wellbeing. Wellbeing in academia is a somewhat slippery concept. It is often measured quantitatively, with the imperative to be ‘well’ or ‘happy’ (Ahmed 2010) seen as an outcome.

In a chapter considering the impact of embodied practices on academics’ own sense of wellbeing, Jennifer Leigh considered that a personal sense of wellbeing is not the same as an institutional definition of wellbeing, which is more likely to equate to productivity:

In the neoliberal drive to control employees, create productive labourers and ideal consumers, wellbeing has become another measurable commodity and tool of governance. Dominant discourses of wellbeing (institutional, governmental, health) articulate neoliberal individualism and responsibilisation for wellbeing. In other words they say that wellbeing is an individual responsibility, putting the emphasis on individual decisions,
behavior, and choices and do not take into account structural determinants like wealth or class.

Research has shown that embodied practices can act as a counterbalance to the dominant Cartesian mind/body disconnect, which views the body as a machine or tool in which to carry the intellect or mind around. Embodied practices could also raise the ‘set-point’ of wellbeing for an individual (Dodge et al. 2012), so that they have a better balance between their psychological, social and physical resources and the challenges that they face. As a consequence some embodied practices, or techniques derived from embodied practices (such as mindfulness) have been co-opted by employers and universities to form part of ‘wellbeing’ programmes designed to reduce the structural problems in the sector with overwork, stress and burnout to individual responsibilities around developing resilience and the ability to ‘manage time’ (Gill and Donaghue 2015). These co-opted techniques often ‘focus on various forms of self-management’ (ibid., 97) and do not incorporate the aforementioned philosophies of self-acceptance that characterise embodied practices. Instead, they appear to be utilised in relating wellbeing to the imperative to be a ‘good’ productive neoliberal worker. (Leigh 2019b, 225-6)

In this context, Leigh was using the term ‘embodied practice’ to describe any activity where the intention was to increase conscious self-awareness of the thoughts, emotions, visual images, sensations and proprioceptions of the mind and body (Leigh and Bailey 2013). Such practices include yoga, martial arts and dance, and could be more internal, such as meditation. In the study, Leigh found that the academics all equated their own practice with an increased sense of wellbeing, regardless of whether they had a chronic illness or disability or not. It is generally accepted that an active lifestyle helps to establish positive health habits and contributes to wellbeing, so this is not unexpected; however, many of the academics interviewed had chronic illnesses, injuries or disabilities. Embodied practices are inclusive in that when the intention is on increasing conscious self-awareness, there is no requirement for physicality. This is important, and differentiates them from physical activities. The distinction is not clear cut, of course, as some embodied practices are also physical, and some physical practices that might be embodied for some people are not for others. One example here could be running – which can be practised meditatively with an intention to
increase self-awareness, or as an opportunity to disengage and listen to loud music. Wellbeing is not just the absence of illness, but an active and ongoing pursuit of something (Blei 2017). Some individuals living with disability or chronic illness may not experience the absence of illness or pain, but that does not mean that they have no wellbeing (Hedva 2016).

The politics of being ill in academia

The role of society and cultural environment within the context of and understanding of illness and illness narratives is well documented (e.g. Kleinman 1982; 1986; 1992; 1995; Good 1992; Ware 1992; 1998; 1999) in medical anthropological and sociological discourses, and increasingly within the medical realm (Hadler and Greenhalgh 2005). Within these conceptualisations, illness is seen as constructed at three different levels, as it is embedded with cultural meaning, but also defined at an experiential level and shaped by medical discourse (Conrad and Barker 2010). Illness symptoms that individuals experience are felt as sensations, but also experienced at an emotional, embodied level as learnt responses to conventions (Trigg 1970). In this sense, illness symptoms are physical manifestations of societal ills and cultural influences (Kleinman 1986) or a lived experience placed within a society or culture (Ware 1998). Through the expressive body’s (Williams and Bendelow 1998) manifestation of pain, individuals’ experiences are validated and become ‘real’. The physical pain can be explained more easily to oneself and to others, and as such represents a protective mechanism that allows individuals to avoid dealing with the underlying emotional issues. In effect, the bodily expression of pain is in lieu of the individual’s verbalisation of pain (Guignard 2013). How individuals report and respond to pain is shaped by cultural and societal conventions (Kotarba 1983). Indeed, the entire illness experience is a social experience that impacts and is impacted by individuals and their relationships to others (Kleinman 1995). Any illness experience therefore needs to be seen in the context of the social. In the personal narrative quoted above, we can see the journey taken as individual pain (and loneliness and frustration) is pitted against the reactions perceived by those around the writer. This illustrates the struggle and turmoil felt when living with chronic illness and pain, and how, within the context of academia – a cerebral (Leigh 2019b) and unforgiving (Bloch 2012) environment – internalised ideals of what is expected exacerbate the intensity of the emotions experienced. We can
see the tension between perfectionism and the reality of stress, pressure and overwork played out in the body and the emotions.

As we have seen earlier in this chapter, academics have integrated the external values of the neoliberal academy to such an extent that they represent a new behaviour and new personal values. In a society that prides itself on the final outcomes and end products of labour rather than the process or labour itself, work has become necessary to find one’s identity. As a consequence, individuals identify themselves and are identified by the work they do (Gini 1998), and when unable to complete this work to the perfectionist standards they set themselves, they are set up into a spiral of rumination that in turn causes both physical and psychological ill health (Joireman et al. 2002). In academia, work identification is so strongly linked to personal identity that individuals will continue to ‘live up to values, even when they are not being monitored’ (Tyler 1999, 19) because they are forfeiting their personal rewards for the benefit of the organisation and the collective (Van Knippenberg 2000), which in turn reduces the need for managerial interventions (Haslam et al. 2000). It is at this level that individuals will perform activities without external controls and without seeking to impress others (Kelman 1958). Academics’ moral commitment to the academy leads to their internalisation of academia’s values of performance and productivity.

But at what point does this become political? The autoethnographic extracts emphasise the tension between the public and private self – the sharp contrast between the internalised ‘feeling shitty’ and the external view of the ideal teacher, the personal journey and need for acceptance and healing and the anxiety of how one is perceived and the realities of facing bullying. These demonstrate how neoliberal values are continually reinforced through academics’ fear of isolation or pronounced change in status (Scott 1971). In the extract ‘Broken Academy, 2017’, rather than modelling a work–life balance to these aspiring academics, we were instead embodying the overwork, stress and fatigue that appear to be endemic, along with the expectation that academic work does not stop when the office day ends (Acker and Armenti 2004). As teachers, we modelled these traits to our students, embodying them in our behaviours and our flesh even as our mouths repeat rote-learned speech regarding balance and wellbeing. We were giving in to the idea of performativity within academia (Pereira 2016). Whilst feeling the constraints and pressures of the measured university and overwork (Acker and Armenti 2004; Gill 2010; Pereira 2016), some also felt the impact of ill health and injury as disrupting forces. It seemed that there are both elements of justification and rationalisation as academics tried to make sense
of the sometimes opposing demands of their practice and work while remaining open to the benefits and ideals of both. This view of being comparatively less productive or unproductive is ingrained in academics’ psyche. On the one hand, the comparisons help individuals identify areas for improvement and further development in order to compete against others within the academic environment of precarious contracts and to succeed in their scholarly work of developing original contributions to knowledge. On the other hand, for people with high expectations and perfectionist tendencies such comparisons lead to feelings of inadequacy or falling short and, ultimately, feelings of failure (Lovin 2018).

The increase in status academics may potentially experience when they are productive and successfully contribute to the knowledge society is offset against the cost of experiencing personal failure instead of achieving higher status, thereby further reinforcing unreasonable standards (Scott 1971). Being ill compounds matters further. In order to manage bodily symptoms most effectively, chronically ill, disabled and neurodiverse academics embrace the flexibility part-time work offers. However, the flexibility that is so hailed results in academics being able to engage fully, which in turn precludes specific positions or roles and thus leads to feeling and being excluded from certain career prospects.

Disability as a personal and political act in academia

In a previous article (Brown and Leigh 2018) we wrote that ticking the ‘I am disabled’ box is a statement and commitment. We could also have asked whether declaring a disability is always a political act. By underwriting a disability, the academic has to be confident and comfortable with identifying as a disabled person. This might change from moment to moment, as can be seen in the extract above headed ‘Being perfect, 2019’. Illness and disability trajectories are often experienced as journeys of acceptance, particularly if these illnesses or disabilities occur later in life or appear suddenly. We can begin to see how declaring a disability can become a political act and what it might take for us to come to that point. Whether we are acting as teachers, leaders or researchers, it is not uncommon for academics to draw attention to unfairness and inequity. It is part of our role within society to educate and to share knowledge, and to be aware of the situations of those around us, to amplify voices that cannot be heard. Just as it is necessary for women to be visible in STEM, and for people of colour to be visible at all levels in academia, it is necessary for those with disabilities to be visible. By declaring a
disability, we can act as role models for our students, showing them that
education and research are possibilities for them, that they have a place
within higher education. We can participate in networks, councils and
committees, speaking up about inclusion and accessibility issues so that
these are less of an afterthought and instead are built into every aspect
of university life. We can live the mantra ‘nothing about us without us’ by
ensuring that academics with chronic illnesses and disabilities are present
and visible and participate in all aspects of academic work and life.

And yet the structural inequalities built into academia are vast.
Within a culture of overwork, it is hard for an able-bodied, well, neuro-
typical academic to thrive and feel supported, as goalposts for success
are constantly moving (Shipley 2018). What then for a chronically ill,
disabled or neurodiverse academic? Ableism, both external and internal-
ised, means that admitting a chronic illness or disability may be
equivalent to confessing to a failing, to laying oneself open to prejudice,
ignorance and discrimination, as experienced in the first autoethno-
graphic extract. If we out ourselves to act as a role model and shed light
on an invisible condition, we are also becoming visible by raising our
heads above the parapet and potentially becoming a target. While an
individual journey towards acceptance of their condition can be a long
one, the moral sense of unfairness can be felt before or as soon as one
falls out of the category of ‘abled’ or ‘well’. What do we do when we feel
a moral imperative to stand up and act as a role model, and yet are not
ready to do so on a personal level? There is a cost to choosing to make a
declaration. If we declare ourselves, and our conditions, this can affect
the way others see us. In the context of fluctuating invisible conditions
(see chapter 8 in this volume), there may be a variation in how each
aspect of disability or illness is experienced, which can in turn lead to
internalised judgements – as seen above, under ‘Coming to terms, 2015’
– of whether one is ‘disabled enough’ to claim that status. It is possible
to experience a feeling of having to justify yourself, to declare your
own condition or disability, to explain your presence or interest in such
activist work. We should not have to declare or explain ourselves, and
yet the real or imagined whispers – ‘why is she here? What’s wrong with
her? She doesn’t look disabled…’ – can colour our authority as activists.
Being ‘out’ might often mean engaging in emotional labour (Gaeta 2019;
Hochschild 1983) in that you are expected or asked to act in a capacity
that supports or advises others, purely because of your own experience.
Often this type of work is unpaid or under-paid. You are expected to be
a point of disclosure for others. Without adequate training and support
yourself, this work can be tiring and draining, and could have consequences for your own condition.

In addition, there are the perceived and potentially real judgements from the outside when you claim a disabled status. If your condition is not visible, is there an expectation that you explain, educate and share personal medical information in order to justify your claim? There is emotional labour (Hochschild 1983) associated with every aspect of this, even contemplating it.

Political engagement and activism are a way of life for many people. Social media such as Facebook have increased political engagement for some (Conroy et al. 2012), and higher education is seen as one of the most important ways to raise political engagement within the population (Hillygus 2005). Political engagement can take many forms, and activism is one of those. For many academics, particularly those working in the social sciences, engagement in research and teaching provides the basis for understanding lived experiences and exploring how to ameliorate situations for individuals or society as a whole. Academic work in this sense can be understood as a form of activism (Chomsky 1969), an action that goes beyond conventional politics, typically being more energetic, passionate, innovative and committed. Political activism may be seen as incompatible with the rationality of research and scholarly engagement (Martin 2009), and yet academics see their work as a stepping stone towards understanding and improving the social world they study. Kirstein Rummery describes her journey of navigating political engagement and activism from a feminist, disabilities studies perspective (see chapter 11 in this volume). However, the intersection of the political and the personal is not one-directional. Given an emotive topic such as ableism, where there is a moral imperative to do ‘the right thing’ as well as comply with legislation and legal duties to work and behave in a manner that does not discriminate against those who have ‘protective characteristics’, political activity and compulsions impinge on personal, lived experience.

It is one thing to be an activist, to take a stand and to ‘get political’ about ableism or any other topic. Many would agree that ensuring that there is an inclusive policy to protect staff or students, and working actively to improve conditions, is a ‘good’ thing. However, there are potentially personal consequences for us if we start to identify as disabled in our place of work, in our writing, teaching or research. Choosing to disclose, or to become an activist, can have implications for the individual, thrusting them into a position of visibility as contrast with the invisibility of many such conditions. Taking a stand, being open and
activist in endeavours, means balancing being a ‘killjoy’ (Ahmed 2017) and challenging injustice with fitting in, going and getting along in order to have and make a career (Murray 2018). If we choose not to disclose, to act up as a role model, then instead we are ‘passing’ – a path not always open to women, people of colour or those with a physical, visible disability (Tatum 2014). Choosing to pass, if we can, is an individual, personal choice. As we have argued here, that choice may in turn be affected by our desire to be political.

References


