Ableism in Academia

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‘But you don’t look disabled’: Non-visible disabilities, disclosure and being an ‘insider’ in disability research and ‘other’ in the disability movement and academia

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This chapter is a personal narrative of my getting to this point in my career, to ‘here’, as a disability law scholar and solicitor with a non-visible disability and a disabled woman working in academia. It is a self-reflection on my experience of the research process and an insider account of my position within that research. I had not anticipated that the well-established philosophy of the disability rights movement of ‘nothing about us without us’ would take on a personal meaning during my research. Framed within the field of autoethnography (Ellis 2004), I am inviting you, the reader, into my world as I have engaged in the research process while completing a professional doctorate in law. Autoethnography is a genre of qualitative, reflexive, autobiographical writing and research that uses the researcher as the subject (Haynes 2011, 135). In this chapter, I am writing about my personal experience of disability within academia. I am engaging with ‘the self’, myself and the interaction between my working life as an academic and my experience of an unseen or non-visible disability. As Ellis et al. (2011, 2) suggest, ‘Autoethnographers recognize the innumerable ways personal experience influences the research process’. My own experience has certainly influenced the research process I have undertaken in the last few years and writing this chapter is a means of recognising that. In
sharing this experience, I am joining forces with other academics who likewise believe their own experience and story is inextricably linked with how they do their research.

The fact that I am writing this chapter at all is a revelation to me. I had very little disability consciousness until I started my professional doctorate, despite living with a chronic illness since 2007. I was ‘in the closet’ (Garland-Thomson 2016) but, to borrow from Kleege (1999), studying for a doctorate has ‘made me disabled’. Given the subject matter of my doctorate, it is important for me to acknowledge that there is an ongoing internal phenomenological dialogue in what I am writing (personal reflections alongside academic writing). This makes for disruptive reading, but the disruption is vital to challenge the understanding of disability in academia. ‘Autoethnography, as method, attempts to disrupt the binary of science and art. Autoethnographers believe research can be rigorous, theoretical and analytical and emotional, therapeutic and inclusive of personal and social phenomenon’ (Ellis et al. 2011, 8). This chapter is framed using this approach because I want to keep the conversation going about the experience of disability and chronic illness in academia – not merely to recognise its existence but to emphasise, through personal narrative, the effect it can have on those of us working in academia and to try to influence and disrupt current academic practice in some small way.

As Goodley suggests, ‘the marked identity of a neoliberal citizen is a worker: willing, capable and able’ (Goodley 2014, 52). For all of us, capability is a capacity to learn and develop and is often assessed on initial employment. Ability is contextual, temporal and often unclear. Willingness, which Goodley rightly puts first, is the neoliberal devolution of responsibility to the individual. Willingness is both what can drive individuals to overcome barriers of capability and ability, but unfortunately can also be used to criticise individuals when they cannot overcome those same (often structural) barriers. In the age of excellence in teaching, research and knowledge exchange in higher education, talking about chronic illness and disability has become increasingly challenging. It is often assumed that the ‘willing, capable and able’ worker can perform to an excellent standard in everything all of the time, but this creates a highly pressurised working environment and this frenetic pace of activity has somehow become normalised. For most, this can make for a stressful and difficult working day, particularly when the many, often clashing demands conflict. The non-visible nature of many chronic illnesses and disabilities can exacerbate this difficulty as it is not
obvious to those we work with that sometimes, although willing and capable, we cannot always perform to those intense standards.

As soon as I embarked upon my research on disability using the law as my frame of reference, I realised that as an academic with a non-visible disability, doing disability research, a more open discussion about disability as experienced by academics was required. Much of what people experience around disability in academia is hidden for fear of stigma and the perception of not being able to 'keep up'. I want to feel welcomed and understood in academia, so that on the days when I cannot 'hyper-perform' then it is OK to say ‘no more today’, without it affecting my ambitions, prospects, collegiality or sense of self. I am also very aware that the profession I have come from, the law, is starting to have similar conversations about disability and in particular mental ill health. In recent years there has been anecdotal evidence about the difficulties faced by disabled people in the legal profession but there has been nothing with a rigorous evidence base. In January 2020, the first research report on disability in the legal profession was published (Foster and Hirst 2020). The authors report on the barriers experienced by disabled people across the legal profession. Their findings suggest that the legal profession is generally poorly equipped to anticipate reasonable adjustments; there is a poor understanding of how disability, impairments and health conditions impact on recruitment and career progression within law; there is a general reluctance to disclose an impairment or non-visible disability because of a fear of discrimination; and the fact that the legal profession continues to operate traditional career expectations and working patterns means that access and progression for disabled people can be difficult. The findings also suggest that a significant proportion of disabled people in the legal profession have experienced ill treatment, bullying or discrimination associated with their disability. Fear of discrimination at the recruitment stage has also been a key finding of my own research with disabled law students, who repeatedly tell me that they are not going to tell potential employers about their disability when they are applying for training contracts or pupillages to enter the profession. Alongside this new report, some writing is emerging on wellbeing in the legal profession of England and Wales (see Collier 2016) and concerns about poor mental health among lawyers are growing in number. Collier (2019) is continuing his research following on from the Junior Lawyers Division Resilience and Wellbeing Survey of 2019, which reports that 48 per cent of respondents experienced mental ill health (whether formally diagnosed or not)
within the month leading up to the completion of the survey. This is an increase on the 38 per cent reported in 2018 and 26 per cent in 2017 (Law Society 2019). Therefore, as disabled professionals working within academia, we are not alone in our experiences.

How did I get to here? Where is ‘here’?

I have been an academic and a lawyer for over 20 years. I teach and research employment law so the world of work and equality has always been important to me. During this time, I developed an autoimmune condition that triggered psoriatic arthritis, a form of arthritis affecting individuals with the skin condition psoriasis. Joints become inflamed, which causes pain, swelling and stiffness. Psoriatic arthritis is a chronic condition that waxes and wanes. What causes it is a matter of continuing research, although it is probably caused by a combination of genetic, immunological and environmental factors. Although psoriatic arthritis is a chronic long-term condition with no cure, there are a number of treatments to manage and control it. I have been on disease-modifying anti-rheumatic drugs since that diagnosis in 2007 in an attempt to slow down the biological processes that cause the persistent inflammation in an effort to control the development of the disease (for more information see the Psoriasis and Psoriatic Arthritis Alliance website, http://www.papaa.org/). In 2019 I developed a secondary autoimmune response known as Sjögren's syndrome, which at times makes writing at a computer for any length of time challenging because of the impact it has on my eyes. Therefore, my own ‘disability’ is now a collection of long-term chronic illnesses which I manage every day through medication and by taking periods of rest from work when I need to. Other than days off to manage pain and fatigue and occasional comments about how tired I look, my chronic illness was largely hidden from my work in academia until I started conducting research as part of my professional doctorate in law. My decision to undertake the doctorate was part of the change to cultures of capability in higher education. I began in 2016 as a result of the intensification and focus on research activity in my own place of work, which, like many post-1992 universities, began to transform its research profile. My doctorate is a phenomenological study, exploring the lived experience of disabled law students navigating their emerging graduate identities (Holmes 2015) and ‘possible selves’ (Markus and Nurius 1986) as they transition into the hyper-competitive world of the
legal profession on graduation. This is inevitably sensitive research, but I had not anticipated that it would also become personal.

As an employment lawyer and a disability law scholar I have always focused on the legal definition of disability set out in section 6 of the Equality Act 2010. Disability is defined as a physical or mental impairment that has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities. The emphasis is on diagnosis of an impairment and its subsequent effect, in particular the effect that the impairment has on things that individuals do on a regular basis. Crucially for those with chronic illness, ‘long-term’ is defined as 12 months or more, so the effect of the impairment has to have lasted for at least a year. Fluctuation and recurrence can all be taken into account by the law. The deduced effect of the impairment is also critical, as most of us with any form of chronic illness would be so much worse without our daily dose of medication. The legal definition is sometimes criticised as being overly medicalised, but up to this point in my professional life it has always seemed appropriate. I am comfortable in myself as being acknowledged as having a disability within the eyes of the law; the law, after all, has been my frame of reference for much of my professional life. I understand my chronic illness to be a ‘physical impairment’ within the section 6 definition and I know what my rights are at work. The duty of reasonable adjustments set out in section 20 of the Equality Act 2010 also protects those rights and my continued ability to work. The duty of reasonable adjustments involves the employer taking any reasonable step, or combination of steps, necessary to remove a disadvantage experienced by the disabled person and which enable the disabled person to work. Arguably the duty also separates disability from other protected characteristics within the legal framework and it is therefore as much a part of the problem as it is a part of the solution.

The Equality Act 2010 brings all protected characteristics, such as sex, race, disability and religion, together into one piece of legislation, all separate ‘silos’ (Solanke 2011) but in theory equal before the law, no one more important than the other. However, some protected characteristics that may have an impact on one’s ability to do a specific job at particular times, such as pregnancy, age or disability, are subject to special rules. Other protected characteristics, such as sex, race, sexual orientation and religion or belief, should have no impact on one’s ability to do a particular job and ought to be ignored by the employer (Griffiths 2016, 162). Anti-discrimination law in England and Wales is designed largely to protect notions of formal equality, treating like cases alike and ignoring the personal characteristics of the individuals
concerned. Disability, however, cannot be ignored and special rules have to be implemented: difference has to be acknowledged, which is often where the problems begin. The only way to benefit from a reasonable adjustment if you have a non-visible disability is disclosure, with all of the complexities of identifying as ‘disabled’. Contrary to critics of the medical model on which the legal definition of disability is based, for me being ‘disabled’ within the legal definition is comfortable. I know where I stand, I know what protection I have as a disabled academic and I know my rights. My legal consciousness is alive and well (Ewick and Silbey 1998). Nevertheless, the discomfort I now feel as I explore further and deeper into my own disability consciousness is sometimes hard to acknowledge.

Disability is the only protected characteristic in the Equality Act 2010 subject to a reasonable adjustment duty, although there has been much academic debate about whether other characteristics would also benefit from such a duty (there are discussions about religion in particular: see Vickers 2010; Gibson 2013; Griffiths 2016). As a result of this unique treatment, those with a disability are sometimes viewed as being treated more favourably than others without a disability, or it can seem that there is some kind of positive discrimination at work. This can play out as a feeling of being separate, different, ‘other’, and when I am at my most vulnerable, asking for a reasonable adjustment makes me feel ‘needy’ – that I cannot function at work without a special chair or special software. Even that word ‘special’ sets me apart. Some people with disabilities do not even ask for the reasonable adjustments they are entitled to because they do not want to appear different. People routinely ask me about my keyboard and my ‘special’ mouse, so I always have to tell them why.

As my research has developed, I have begun to appreciate that the legal definition of disability plays just one part in this complex area, but it is a definition that I remain comfortable with. However, in developing a theoretical perspective for my professional doctorate I have come to appreciate that there is no one overarching definition, theory or model of disability: there are many, and this has led me to question my legal position as a person with a disability, my own position in the disability movement and my identity. Inevitably, however, difference has to be acknowledged. As a lawyer undertaking my doctorate, I have had to explore disability studies alongside the law, and as suggested by Kanter (2011, 406), ‘Disability Studies offers an appropriate lens through which we can view the legal profession, and the meaning of difference within the legal system, and society’. Kanter goes on to say that Disability
Studies ‘offers the law and legal education the opportunity to critically examine the role of “normalcy” within the law [...] it requires us to recognise, appreciate, and most importantly, value difference among us’ (Kanter 2011, 406). Difference sets us apart, makes us ‘other’ within the legislation, within society and arguably within academia. For those of us with non-visible disabilities, the difference is intensified, but difference really does make a difference.

**My ‘coming out’**

The immediate ‘disclosure’ process at work began quite soon after my diagnosis, but only to a very small number of people: close friends who also happened to be work colleagues. They understood when I had ‘off’ days, when I was truly fatigued as a result of my condition and when I needed to rest. To everyone else, it was ‘business as usual’. Acknowledging my legal rights, I actively wanted to be dual-tracked in work for our capability procedures, knowing that when I needed days off because of my disability, they would not count towards any kind of performance or capability management. However, this was confidential between me and human resources: I understood my rights, after all. For a long time, this is as far as disclosure went.

As part of my doctoral research I presented a paper on disability and positionality in research at the ‘Ableism in Academia’ conference from which this book arose. This was not a law conference so I did not think anyone would know me and I felt ‘safe’ disclosing my disability to a room full of colleagues (strangers) from other higher education institutions, who were familiar with what I was going through. What I had not fully appreciated was that because this was a highly accessible conference, it was to be livestreamed over the internet. As a result of this livestreaming other people were able to see me, including a colleague from my own institution. Due to the power of social media, she saw me disclosing my disability in what was actually quite a public forum. This accidental encounter led to us doing a joint paper at our own institution’s doctoral and faculty research conference in June 2018. Our paper was about sharing and disclosing our respective non-visible disabilities in our research but from two very different perspectives. I had been grappling with reflections on my own chronic illness and the impact it was having on my research and consequently my academic identity, while she, I discovered, had recently published an article about her own experience of anxiety and depression at a particular time in academia.
(Campbell 2018). For her it was suddenly out there: everyone would now know she had suffered with bouts of anxiety and depression and had been off work for three months. Ironically, it had particularly come to the fore during her own research and professional doctorate. For me, it was still largely hidden.

After the faculty conference paper, what became clear in the feedback we were given was that very few people ever talk about disability, particularly the influence of their own disability in their research, and that we were suddenly viewed as ‘brave’ and ‘courageous’ for sharing. To be perfectly honest I do not feel ‘brave’ or ‘courageous’ and I am not really sure why I need to be. Bravery and courage, words synonymous with endurance and battle, suggest that I have a choice in accepting this sometimes daily encounter with pain and discomfort, that I have willingly entered the fray to tussle with the physical embodiment of my illness. This could not be further from the truth. It is not a battle or a struggle, it is just something I now have to tolerate. Just part of who I am. What really interests me, though, is what led to people referring to us as brave and courageous. Why do so few people talk about their chronic illness or disability, particularly when it is non-visible? There is a risk of course associated with disclosure. As already suggested, disability is ‘other’, different. The legal definition in particular forces us into that position because of the emphasis on the individual impairment and – to link back to being brave/courageous – implies that this is a personal tragedy that we have to endure and that somehow we are now lesser or part of a problem that needs to be fixed by an adjustment. I come back to a discussion on disability theory below, and explore why some of it is problematic for me, but for now, let us just say that in my naivety I had never really thought what impact this examination of disability could or would have on my willing and capable self. I had never thought of myself as ‘other’, or of the stigma associated with being ‘other’, but for now it is enough to acknowledge that my ‘spoiled identity’ (Goffman 1990/1963) was very much coming to the fore during the research process. Sometimes, though, I have to take a step back and think – really? Is this who I am now? As Brown and Leigh suggest, ‘Illness and disability trajectories are often experienced as journeys of acceptance, particularly if these illnesses or disabilities occur later in life or appear suddenly’ (Brown and Leigh 2018, 986–7). I have gradually started to realise as part of this research process that this is not just about my legal rights; it is also about how I have started to reconstruct my own identity as an academic with a disability, a disabled academic. This is the journey of acceptance I have begun.
Who am I now that this has happened?

Although I remain comfortable with the legal definition of disability and where I fit in that, as someone with a chronic illness I am not sure I am what society would consider to be a ‘disabled person’. The legal definition confirms to me that a chronic illness is a disability. It is much harder to talk just in terms of ‘illness’ or ‘disease’. But for my medication I would find life a lot harder and debilitating. The nature of my impairment is often varied, as is the effect of the impairment, which inevitably leads to a variety of legal and personal responses. Chronic illnesses are not fixed disabilities; rather we have good days when we might ‘not be’ or ‘feel’ disabled at all, and other days when we are very debilitated by our conditions. The various theories of disability do not necessarily account for this fluctuation and the position of chronic illness within the disability movement is often contested (see Barnes and Mercer 1996).

Unseen, hidden or non-visible disabilities, which are not readily seen or immediately obvious to others, also raise many issues about the presentation of self in everyday life (Goffman 1990/1959). For those of us with chronic illnesses our conditions can go largely unseen and this can present a problem for us within our workplaces and wider society. My own condition is not constant, which is the case with many chronic illnesses. It does fluctuate and ‘flare’, but it is always there, even if I can hide it some days. If I announce my condition, its invisibility becomes a concern – will people believe me? Am I actually disabled within the legal definition? What adjustments should I get, and do I really need them? Can I keep up on a daily basis in this hyper-challenging environment? Am I sick? Am I well? Am I disabled? Too many questions. Where do I go to find answers, and will the various disability theories help me position myself somewhere?

Two 'models' of disability prevail – the social model and the medical model. Both have been theorised, questioned, criticised and debated, and both have been expanded or rewritten to some extent. The British version of the social model of disability, first expressed by the Union of Physically Impaired against Segregation (UPIAS), stated, ‘In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS 1976, 3). This social model of disability was developed further by Oliver, who emphasised the need for a new way of looking at disability (Oliver 1983; 1990). The social model suggests that society over-medicalises disability,
situating the problem firmly with the individual and the ‘personal tragedy’ of disability, rather than where it should lie, i.e. with society. This is an important definition – I do understand that – and crucially it sparked the development of the disability movement in the UK and political activism for disabled people. Society does disable, there is no denying that: I have seen it in practice on many occasions. But am I disabled within this definition? Probably not. I, personally, am not isolated or excluded. I am still *willing, capable* and, for the most part, *able* and I fully participate in society. Nevertheless, the medicalised impairment model on which the legal definition in the Equality Act 2010 is based does set me apart from colleagues because of the need for diagnosis of an impairment and subsequent requests for reasonable adjustments. But it is important to me, because without it I would not have been able to ask for the adjustments that I need to make my working life a possibility. In my own research with disabled students, all of whom unexpectedly presented with non-visible disabilities, I ask them: when they think of disability, what do they see? They all said ‘someone with an obvious physical disability’ or ‘someone in a wheelchair’. They did not see themselves as having a disability even though when I went through the legal definition with them, they all acknowledged that they would fit squarely within it. Those same students would not see me as disabled, and although my chronic illness sets me apart in some ways, for the most part society does not even know that I have any impairment/disability at all. Whilst the social model would ignore my impairment, I cannot. The pain at times can be debilitating, the fatigue overwhelming and therefore my own lived experience is important. If all societal barriers were removed as advocated by the social model, my own physical impairment would still debilitate.

Goffman suggests disability is ‘stigmatized’ as a negative identity (Goffman 1990/1963). In his view, members of this group are assumed to be tainted or inferior in some way. This in turn prevents the individual from being included in society. In considering this stigmatised identity Loja et al. write that ‘The concept of normality, embedded in the medical model, has been at the core of the othering process that has shaped the understanding of disability as a physical, moral, emotional, mental and spiritual deficit’ (Loja et al. 2013, 198). I do experience this othering from time to time, particularly when asking for reasonable adjustments. Campbell states that ‘inscribing certain bodies in terms of deficiency and essential inadequacy privileges a particular understanding of normalcy that is commensurate with the interests of dominant groups (and the assumed interests of subordinated groups)’ (Campbell 2009, 11).
Therefore, this acknowledgement of normal and difference is problematic and contributes to the ‘othering’ of disability. Nevertheless, for those of us with non-visible disabilities this is not always the case. Controversially in some ways, we can choose who we are in front of others. Because we can ‘pass’, we can decide whether or not to assume this negative identity on the outside. I am not suggesting that this in any way helps, as we still have to decide whether or not to disclose our disability at some point. However, up until the point of disclosure we do not have to acknowledge this ‘othering’, except in our own minds.

I do appreciate why the medical model is problematic within the disability movement. Nevertheless, as an academic with a chronic illness that fits squarely within the medicalised legal definition of disability, I struggle to associate with the social model. I have to prefer Shakespeare’s critical realist approach to disability. Shakespeare argues that “social-modellists” would claim that so-called “medical-modellists” assume that “people are disabled by their bodies”, whereas they say instead that “people are disabled by society, not by their bodies”. I would argue that “people are disabled by society and by their bodies” (Shakespeare 2014, 75). This is my authentic self. I have become disabled because of how people view me with my arthritis (once they know) and what I imagine people think of me with my arthritis (once they know). My body does, however, let me down on occasion, and work practices can be challenging. Being disabled by society only happened once knowledge of my chronic illness seeped out into the world. But my impairment or illness and the impact it has had on me has been my reality for years. As Williams suggests, ‘endorsement of disability solely as social oppression is really only an option, and an erroneous one at that, for those spared the ravages of chronic illness’ (Williams 1999, 812).

Thomas (1999; 2004) developed the social model to incorporate ‘impairment effects’ in an attempt to account for difficulties caused by medical conditions and impairments. In keeping with Thomas’s relational interpretation of the social model of disability, my relationship with society changed once I disclosed my disability and my impairment does have an effect on me. Likewise, Shakespeare argues for an alternative approach to the social model, that of interaction between individual and structural factors (Shakespeare 2014, 74). Shakespeare acknowledges similarities between Thomas’s relational approach and his own interactional approach. Both are relational in that disability is a ‘relationship between intrinsic factors (impairment, personality, etc.) and extrinsic factors (environments, support systems, oppression etc.)’ (Shakespeare 2014, 76). Nevertheless, I, like Shakespeare, disagree with Thomas’s
approach as it defines disability in terms of ‘social oppression’ (Thomas 1999, 60). Shakespeare suggests that ‘to define disability entirely in terms of social oppression risks obscuring the positive dimension of social relations which enable people with impairment’ and goes on to define ‘disability as the outcome of the interaction between the individual and contextual factors, which includes impairment, personality, individual attitudes, environment, policy, and culture’ (Shakespeare 2014, 77).

I have to reflect on the impact of all these theories on my own identity, professional and otherwise. The focus for me is not necessarily always on my own bodily impairment, although there are days when it lets me down and I feel the impact of non-normalcy on what I am doing. For me it is my emotional and mental self that imposes ableism on my own identity. I have come to see life in a different way and this has filtered through into my working life. I could argue that before the development of my chronic illness I felt I could do anything, and some days I still feel like that. Now, in my own mind, I know I am different in some way. Some days I cannot compete at the same pace. However, this difference does bring with it other advantages. Slowing down is important for all of us. Why do we constantly have to respond to this ‘culture of perfectionism’? I am willing and capable – why isn’t that enough? Many colleagues who do not have any form of disability or chronic illness struggle to keep up at times. Why has this become the new normal? Maybe it is down to those of us with a chronic illness or disability to challenge the mandatory demand for excellence in everything in academia. However, I do not feel socially oppressed. Once I disclosed, yes, my interactions changed, but some of that has been wholly positive and it has led to fruitful conversations in our faculty about disability and non-visible disabilities in particular, for staff and students alike.

It is important to affirm ‘the diversity of bodies as a plus in a pluralist and inclusive society’ (Loja et al. 2013, 200). In the struggle against ableism this recognition is crucial, and higher education institutions would do well to incorporate this diversity into their thinking on academic progression, teaching and learning strategies and employment policies. As Pinder writes, ‘A successful employment policy needs to address the complexity and ambiguity of disabled people’s experiences, as well as draw upon the common threads which underpin their struggle to compete economically in an ableist [sic] society’ (Pinder 1996, 149). This is how I feel about academia. If we are to compete in the current version of higher education with its rival interests of excellence in teaching, research and knowledge exchange then higher education institutions must address the complexity and ambiguity of our experiences
as disabled academics. It is also important that universities acknowledge how many of us there actually are. As Brown and Leigh ask, ‘where are all the academics with disabilities, chronic illnesses or neurodiversity?’ (Brown and Leigh 2018, 4). I only have to look at my own Twitter feed to work out that there are many of us, and of course that is just a small snapshot of the number of academics living with disability, chronic illness, mental ill health and neurodiversity. In Pinder’s essay (1996) she writes about two people with arthritis: one, Peter, at the start of his diagnosis with rheumatoid arthritis, and the other, Lucy, with psoriatic (my own version of arthritis). In this study there is an acknowledgement of the discomfort that exists between not only disabled people and the able-bodied, or ‘temporarily able-bodied (Zola 1989, 406), but also those who are disabled, the wider society and those who exist in the liminal space between these worlds – which I refer to below as my ‘shade’.

The social model of disability as devised by Oliver (1983; 1990) has denied the impact of impairment. The disability movement that largely embodied this model fails to acknowledge the part that chronic illnesses play in disabling people. Chronic illness is still seen as ‘medical’ and therefore falls outside its province. I would suggest that the voices of the chronically ill, who ‘weave in and out of disability’ (Pinder 1996, 153), have been relatively muted in the disability movement. ‘The contradictions inherent in relying primarily on a social model of disability to explain the difficulties the chronically ill and disabled people face at work cannot be ignored’ and ‘the experience of difference within difference needs to be acknowledged’ (Pinder 1996, 153). Pinder suggests that feminists have already paved the way for this and the differences between women are crucial, just as the differences between disabled people are important. Of course, just as the disability movement lacks unity around a single definition, so does the feminist movement. However, feminist disability scholars have picked up the baton and are arguing for an all-encompassing and inclusive theory of disability. Feminist Liz Crow has criticised the social model for neglecting the individual experience of impairment: ‘As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against disability’ (Crow 1992).

The emphasis on difference brings us back to the legal definition and I would argue that difference has to be acknowledged as long as it does not suppress diversity within disability itself or reinforce false
categorisation or hierarchies. Experience and voice have to be valued. As much as I want to ‘pass’ as ‘normal’ or ‘able’, as maybe I have not fully accepted my identity as a disabled academic, I do worry that in doing so I am denying an important role I could play in changing the way academia views disabled people. My own experience has been on the whole very supportive, and that is because of my great colleagues and my own head of department. I have, though, heard so many distressing stories. I cannot deny that my physical differentness is influencing the way I now see the world and I question the systems developing within higher education. When I realise that I cannot keep up, I worry about my position, but I still produce excellent work, I never fall behind, I push myself to present myself as capable and able to my students and colleagues – even though some days I would dearly love not to. If I do my job well, with no complaints, why do I feel inadequate some days? This is because of the pervasive culture of perfectionism in which we now operate.

The labour market of higher education emphasises what Pinder (1996, 152) refers to as ‘productivity and performance’. We need to be always productive and always performing. I am productive and I do perform, but not always at the pace higher education demands. Past achievement seems to have no lasting currency. Achievement is no longer ‘bankable’; it is now (almost instantly) reframed as the new baseline for which more or different achievement is urgently required. You see it everywhere – schooling, assessment, the job market, workplaces.

**Why does any of this matter?**

Doing my professional doctorate has made me more aware of my own position in the research process, as a disability law scholar and a disabled academic doing disability research. Relating to, or imagining, the likely experiences, concerns and claims of the participant group in my research – disabled law students – can be beneficial when using interpretative phenomenological analysis, but it does not require the researcher to have ‘insider’ status. Nevertheless, the research has required me to negotiate access to insider accounts and relate to and reflect on the experiences of the participants (Smith et al. 2009). My research has cast a spotlight on my disability and my disability is influencing my research and my position within it. My experience as a disabled academic in the competitive world of higher education has led me to question the ableism within academia but also within the professional employment we are preparing or ‘training’ our students for. We count our students in and
count them out, and assume they are on a linear trajectory to professional graduate employment. However, this is not always the case for the disabled student.

As a disability researcher with a non-visible disability, I am also presented with an ethical dilemma – whether or not I should reveal my own disability to my research participants. Disclosing my disability to students in the institution where I work is revealing a part of my life that I might prefer to keep private. My legal training demands empathy but impartiality. My disability and my place of work also being the site of my research give me ‘double’ insider access, and the challenges of my position in my own research are compounded by my own identity as an academic, as a lawyer, as an academic with a disability, as a disabled lawyer – the list could go on. I have faced a number of dilemmas I had not anticipated when I started this doctorate, but there is no doubt that my interest in this research has stemmed from my own ill health. While exploring my ‘position’ in my research I have been forced to explore the nature of being an insider in research. Mercer (2007) explores the various concepts of ‘insiderness’ and I am using her work to explore my own questions about conducting insider research at my place of work with students who are part of my teaching cohort, while also reflecting on my position as a ‘disabled’ researcher and disability law scholar. My position has become an essential part of my research and the internal dialogue continues. Do I have more empathy or less? Do I understand the group better or not? Is my data going to be richer or not? I have access, the setting is familiar, I can build rapport, I have a shared frame of reference in the law and disability. However, I do not want to ‘contaminate’ my data and my non-visible disability means I can remain silent about my own experience of disability.

Alongside the acknowledged ‘insiderness’ of my professional status as a lawyer, my power as an academic and my visible signifiers of position, mine is also a ‘secret’ insiderness in that after much discussion and deliberation, I have chosen not to disclose my disability during the research process. I am, after all, ‘temporarily able’ and I am not ready to ‘out’ myself in this way in the interviews I am undertaking as part of my research. This doctoral research is not about ‘me’ and I do not need to disclose and, as I am still questioning how much disability is a part of my own identity, I do not want to delve into my own position with my research participants. I do, however, fully acknowledge the influence I have had on my research and I would suggest the research has become richer because of it.
Where does this get me?

Recently, I have come to identify myself as being part of Frank’s (2004) ‘remission society’, which brings its own discomfort. I am declared medically ‘in remission’ as my chronic illnesses are largely ‘under control’ because of the medication I take. I have fewer obvious flares; my pain can be lesser. Most people think that individuals are either well or sick. ‘Sickness and wellness shift definitively as to which is foreground and which is background at any given moment’ (Frank 2004, 163). In the remission society, ‘the foreground and background of sickness and health constantly shade into each other’ (Frank 2004, 163). This is Sontag’s ‘kingdom of the sick’:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag 1978, 3)

This ‘shade’ has become part of my identity. Some days I inhabit the ‘kingdom of the sick’, but unlike Sontag’s suggestion, I never get to fully leave this domain. Because of the stigma associated with illness and disability that we have yet to overcome, sometimes it is easier just to lie. I can exist in the world of the well because of medication and so I can ‘pass’ as ‘normal’ and ‘able’, even if only temporarily on some days. As Goffman suggests, the rewards of being or appearing ‘normal’ are such that most of us who are in such a position will choose to do so at some point and conform to ableist views of the world and what it is to be ‘normal’. However, in remaining silent for so long and in this context, I am not facilitating the need for change in academia about how disabled academics are viewed and how much our presence and our research matters.

It is fair to say all of this has led me to see things differently. This autoethnographic narrative has been used to explore my own position in my research as part of the research process but also my own identity. I have transitioned from a practice-based lawyer to a qualitative researcher and the influence of my own personal phenomenon of a hidden or non-visible disability cannot be ignored. Much as I exist in the shaded area between health and sickness, so too do I exist in the shaded area between insider and outsider status in my research, thus reinforcing
the continuum. However, this transition is still in a state of flux and I
certainly do not have all the answers but I am now content to contribute
to the conversation.

Returning to Goodley, ‘the functioning neo-liberal self is an
able-bodied and minded one. This is a self that is widely desired. Such
visions of selfhood threaten to neutralise alternative ways of becoming’
(Goodley 2014, 28). In one sense, I have ‘become’ someone else in doing
this research. I am willing, capable and able – just not always at the same
pace or always at the same time. I have decided there is nothing wrong
with that. Academia needs to acknowledge this difference, which is
crucial in the functioning of our legal rights in the workplace as academics
with disabilities (visible or otherwise). It is crucial to acknowledge how
much we contribute to academic life and how we see ourselves in wider
society. Nevertheless, acknowledging and respecting this difference is
important for our own wellbeing and our voice and experience must be
heard. I would strongly argue that this should be the new ‘normal’. After
all, aren’t we all exploring alternative ways of becoming? Aren’t we all
constructing or reconstructing our identities as our position in the world
changes as we age, as we develop illness, as we are promoted, as we
retire, as we take on new challenges?

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