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Introduction: Theorising ableism in academia

Nicole Brown

In the contemporary context of social rights and activist movements such as those associated with combatting sexual harassment, gun and knife crime or climate change, we can observe a typical pattern of public responses. These movements offer voices to those who are marginalised, and indeed provide the confidence needed for many people to stand up for specific issues. This, in turn, increases awareness and understanding of and for the marginalised. However, the stronger specific movements become, the more likely it is that the general public will experience a sense of saturation, leading individuals from marginalised groups to be sidelined once more. Collections like this one are necessary to bring into the public consciousness the matters of those who are marginalised and who negotiate difficult contexts.

Traditionally, academia has been seen as an ivory tower, as elitist and privileged. However, publications in the first decade of the twenty-first century have highlighted some of the realities of contemporary academics. Such publications have focused on the narratives of women of colour in academia (Gabriel and Tate 2017) and the depiction of neoliberal academia from a feminist perspective (Taylor and Lahad 2018), emphasising how navigating academia is a personal and political endeavour requiring intense emotion work. To further debates in and around academia, this collection focuses on experiences relating to disabilities, chronic illnesses and neurodiversity within higher education. Drawing on theoretical frameworks usually associated with sociology, anthropology and disability studies, for example, the contributors in this collection theorise their personal experiences and contextualise these

within the wider societal, social, cultural and academic discourses. The contributions in this collection therefore provide an insightful snapshot of what it means to be 'othered' in contemporary neoliberal academia.

Context of contemporary higher education

Over the last three decades the UK higher education sector has seen drastic changes: it has become marketised and bureaucratised (Hussey and Smith 2002; Tilak 2008; Gewirtz and Cribb 2013). Government cuts to direct funding and the introduction of new funding systems have devolved financial responsibility to higher education institutions (Thompson and Bekhradnia 2010; Department for Business Innovation and Skills 2011). This means that institutions are under increasing pressure to attract students who are effectively the financiers of their own studies, and higher education institutions compete directly for students. The process of universities turning into corporate businesses is stimulated further by globalisation and internationalisation (Law and Hoey 2018). As emerging Asian and South American economies look towards English-speaking countries to provide education for their students, competition within the UK higher education sector becomes fiercer, particularly as international students bring in more money than students from the UK. The result of such cost-benefit approaches is consumerist behaviour on the part of students and their parents and a tertiary sector that is about meeting students' expectations, bettering value for money, improving employment opportunities, enhancing employability skills and achieving specific outcomes (Hussey and Smith 2002; Department for Business Innovation and Skills 2016; Robinson and Hilli 2016). These external factors related to neoliberalism within higher education, and the resultant changes to academic career paths, budgetary developments and student intakes impact academics' roles and identity (Marr and Forsyth 2011; Henkel 2000). And yet working in academia continues to be romanticised (Lovin 2018) and is still seen as a career worth striving for (Bauman 2001) as it evokes the image of like-minded individuals sharing knowledge and expertise in collegial collaboration for the betterment of society and the common good (Lewis 2008; Tilak 2008). Academia represents privilege, autonomy and flexibility, although having freedom and autonomy does not mean academics can do what they want (Bauman 2001). They are continuously required to carry out high-quality research, acquire relevant research funding and produce reputable research publications (Abouserie 1996; Watermeyer

2015). This is in addition to teaching commitments and consistent engagement with the public to ensure long-term research impact. The universities' subjection to consumerism is further compounded by government initiatives that link student fees to institutional achievements such as research outputs or teaching excellence. Measures to ensure that targets are met and that courses retain credibility include the introduction of benchmarks, frameworks and criteria. These policies and initiatives resulting from the demand for accountability lead to managerialism and bureaucratisation within higher education (Winter 2009; Waitere et al. 2011). Paradoxically, universities are under pressure to perform and demonstrate high levels of achievement, but at the same time concede to massification of higher education (Harris 2005). The pursuit of excellence is crucial if an institution is to gain higher status and a better reputation across the higher education market, which in turn attracts more students, more staff and more funding. Excellence therefore leads to prestige, a relational value against which institutions measure themselves (Blackmore 2016). For individuals, working in a prestigious institution is a motivation to increase their productivity and the quality of their own work as a way of contributing to the institution's collective prestige (Blackmore 2016). The premise for such a rigid regime of productivity, effectiveness and excellence geared towards tangible outcomes and outputs in order to support the prestige economy (Blackmore 2016) of a university is a standard, normative, fully able and abled being. In brief, ableism in academia is endemic.

Studies in ableism

The difficulty with conceptualisations is employing a definition that is generic and encompassing enough to include as many perspectives and theoretical lenses as possible, yet specific and precise enough to allow theorisations to be contained. Ableism is no different. As a term, ableism evolved in the 1960s and 1970s from social rights movements within the disability communities in the UK and the US (Albrecht 2006). Ableism then described the prejudices and discrimination the disability community was faced with. In this original iteration, ableism was a specific form of -ism relating to and experienced by those whose bodies or whose 'physical, mental, neuronal, cognitive or behavioural abilities' (Wolbring 2012, 78) were not standard, normative, typical, but somehow different. The development of the concept is closely linked to the cultural lens within disability studies and so ableism is described as

a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (Campbell 2001, 44)

As explorations of lived experiences increased within disability studies but also beyond, there came the recognition that ableism affects more than visible forms of disability. Over time therefore the term evolved to signify an ‘umbrella ism for other isms’ (Wolbring 2008, 253). Consequently, in public discourses ableism has become synonymous with experiences of racism, sexism and ageism, but also of invisible disabilities and chronic illnesses, the ‘non-normative other’. Scholarly explorations have warned about the dangers in separating studies in ableism from disability studies and the risks individuals take by researching ableism without knowing the breadth and depth of the disability studies canon (Campbell 2009). At the same time, however, personal experiences cannot be dismissed. While ableism has been defined (see e.g. Campbell 2009; Wolbring 2012; Dolmage 2017) and an outline for how to study ableism has also been developed (Goodley 2014), little work has yet been undertaken in relation to the higher education context. This collection calls into question the many binaries we encounter: academics’ multiple identities, which are often at odds with one another; the role of internalised norms, which we all strive for; the scientific research we undertake, which is opposed to the validity of personal experiences and personal positioning. And in the middle of all this sits the concept of the perfect academic. It is therefore the context of higher education with its emphasis on performativity, efficiency, productivity and personal reflectiveness that requires our attention. This is where individual experiences often jar with the focus of the disability studies canon. Disability studies emphasise social and societal barriers and challenges, reject the (bio)medical model of a body at fault and seek to embrace disability as an asset and as a different way of working. Within academia, where perfectionism, productivity and excellence are internalised, individuals may not necessarily be able to subscribe to this philosophy. This is why the concept of ableism and studies in ableism provide a helpful theoretical framework and an effective lens to theorise and make sense of personal experiences.

Ableism in academia: Disabilities and chronic illnesses in higher education

Rather than embracing difference as a reflection of wider society, academic ecosystems seek to normalise and homogenise ways of working and of being a scholar. Academics with chronic illness, disabilities or neurodiversity are practically unseen and starkly under-represented in comparison to students with disabilities or disabled people in the general public (Brown and Leigh 2018). More recently, interest in ableism in academia has grown with publications such as *Academic Ableism* (Dolmage 2017), *Negotiating Disability: Disclosure in Higher Education* (Kerschbaum et al. 2017) and *Mad at School: Rhetorics of Mental Disability and Academic Life* (Price 2011). However, to date no attempt has been made to theorise ableism in academia. This book provides the interdisciplinary outlook on ableism that is missing. Drawing on research data and personal experiences, members of academia theorise and conceptualise what it means to be and to work outside the stereotypical norm. The focus of the book and its outlook on ableism are not grounded within approaches commonly associated with disability studies. The theoretical conceptualisation of ableism is set within the context of the variety of knowledge production in academia. As such, contributors define disability, ableism, chronic illness and neurodiversity on their own terms rather than following the prescription of a specific interpretative model. Through engagement with scholarly debates and theorisations of the body and embodiment, and emotion and identity work, and drawing on theories from sociology, disability studies, education studies and the like, this book foregrounds how individuals make sense of their experiences of ableism in academia. It is this particular approach to theorising disability and chronic illnesses that explains why some conceptualisations and outlooks are more prominent than others. Throughout the book, many contributors have used Goffman's *Presentation of Self in Everyday Life* (Goffman 1990/1959) and *Stigma: Notes on the Management of Spoiled Identity* (Goffman 1990/1963) to make sense of their experiences, while others refer heavily to feminist and poststructuralist philosophy. Three contributors used poetic inquiry to theorise and make sense of their experiences of ableism in academia, which resulted in a poetic form of expression. As a scholarly endeavour and a specific form of arts-based research, poetic inquiry is a qualitative research approach that helps

to provide new insights and learning; to describe, explore, discover, problem-solve; to forge micro-macro connections; to engage holistically; to be evocative and provocative; to raise awareness and empathy; to unsettle stereotypes, challenge dominant ideologies, and include marginalized voices and perspectives; and to open up avenues for public scholarship, usefulness and social justice. (Leavy 2015, 21–7)

Using poetry as/in/for inquiry connects the private with the public, the specific with the general, the personal and intimate with the cultural and social to 'lay naked the taken-for-granted assumptions and social structures' (Faulkner 2020, 7). As this book seeks to provide insight into the wide range of issues and concerns of those who may not fit the expected norms of the stereotypical academic, so its form was opened to poetic inquiry.

As a result, this book offered contributors the all-important space and opportunity to explore and theorise personal experiences. More specifically, the aim of the collection is to provide an open engagement with ableism issues that is not confined by or restricted to disciplinary conventions or categories. Therefore, researchers and students will find the book interesting, as it offers a topic that has yet to be covered in this specific way of theorisation and personal experiences. Higher education researchers may be used to interdisciplinary approaches, but disability, chronic illness and neurodiversity are not commonly explored in these ways. For disability studies researchers, the approach of combining disability, chronic illness and neurodiversity will be novel, as from a disability studies point of view the three are seen as different experiences. From an ableism studies point of view, however, they are clearly related. Researchers from sociological studies will find this collection particularly fruitful and interesting, as the societal ramifications are laid bare. For staff and students in the tertiary sector this book provides theory and conceptualisation, theorisation and also personal interpretations of ableism in academia. Academic and non-academic staff members, as well as students, will benefit from the combination of theory and experiences. The debates around ableism, equality, disabilities and inclusion are meeting the current trend within academia, and this book offers a wide range of readings.

The opening chapter by Claudia Gillberg is concerned with knowledge production and ways of working in academia, while also addressing prejudices and expectations of disabled bodies. In her chapter, Gillberg argues that disabled people are often seen as non-academic or

intellectually weaker and therefore, for her, education and participation in academia are an issue of social justice. Her suggested way forward is to break down existing norms and conventions and for academia to reflect differences in knowledge production accordingly. In her chapter, Francesca Peruzzo also explores ableism from personal experiences, but from the position of a non-disabled academic researching disabilities. Drawing on Foucault, Peruzzo questions and challenges the expectation that only the disabled should be engaged in ableism studies. Thereby, Peruzzo hints at the normative body within disability scholarship needing to be an otherwise non-normative body. The chapter by Nicole Brown reports on an empirical study with academics with fibromyalgia. The author focuses on how disclosing a condition in academia is a sensitive issue, requiring individuals to grapple personally and privately as well as publicly with appearing weak. Disclosure in this sense exposes individuals as vulnerable and therefore sensitivity is required in responding to disabled or chronically ill colleagues. Divya Jindal-Snape's poem 'Fibromyalgia and me' is a moving expression of the narrative I's self-doubts linked with the experience of having a contested, invisible illness. In her poem the author acknowledges the significant role the illness experience plays, but at the same time emphasises that there is more to an academic self than an illness.

The subsequent chapter by Nicola Martin reports on findings from a research project and so provides evidence-based insights into the lived experience of disabled academics. Using the findings from her research Martin offers a solid basis for future steps, making clear recommendations on how to develop more inclusive practices within academia. In her contribution Alice Andrews explores Derrida's concept of autoimmunity and McRuer's crip theory to theorise what it feels like when one's body is attacking itself, thus one's self. In her discussion of ableism Andrews specifically discusses the contemporary context of the neoliberal academy in the United Kingdom. In doing so, Andrews considers, questions and critiques the position of the standard normative self and the pressures of advocating specifically for those who do not fit the mould. Elisabeth Griffiths explores the tensions she has experienced as an academic interested in disability rights and disability research, while at the same time looking well and passing as non-disabled. Starting from a very personal experience of disclosing a disability and of dealing with the consequences of that disclosure, Griffiths reflects on how specific forms of knowledge production and particular ways of working are normalised and disability is not considered appropriately. Ultimately, she asks for a wider acceptance of differences.

The theme of being different is also explored in the chapter by Carla Finesilver, Jennifer Leigh and Nicole Brown. The focus of their chapter lies with the expectations that disabilities and illnesses take specific forms and kinds. Often such conditions are interpreted as binary, consistent and visible, when in reality the lived experience of disability and chronic illness tends to be one of fluctuating invisible symptoms. The personal narratives in this chapter highlight the tensions in trying to meet expectations while at the same time needing to negotiate the specificities of one's body. Jennifer Rode's contribution is the poem 'Imposter', a powerful stream of consciousness from the point of view of someone whose 'different' body and mind impact their academic work, while simultaneously causing self-doubt. The work by Jennifer Leigh and Nicole Brown demonstrates that disabilities, illnesses and neurodiversity are not only an external and public matter, but also a personal concern. They argue that ways of working in academia are often internalised to such an extent that individuals feel committed and obligated to fit within the existing norms, and thereby touch upon how the structural and political aspects of academia impact upon the personal and private.

Kirstein Rummery's exploration of the personal and political is the author's journey between social activism, political campaigning and an academic career. Writing from the perspective of a person who has acquired lived experience of disability over the course of several years, Rummery explains the barriers to political engagement as a person with disability, and the tensions in the public image of a campaigner and activist afforded by her institutional membership. Drawing on her extensive professional expertise regarding the studies in ableism, Fiona Kumari Campbell's chapter discusses the ramifications of disability and accessibility policies and reasonable adjustments. Campbell highlights how ableism equals social exclusion. She urges us to rethink our current approaches to inclusion to ensure that well-meant practices do not humiliate individuals. This chapter is followed by El Spaeth's 'A little bit extra', in which Spaeth thematises reasonable adjustments. The poem represents a raw account of how chronically ill or disabled individuals are misunderstood and othered in academia.

Nicole Brown and Jennifer Leigh use the conclusion to bring together key themes of the individual chapters and to outline what it meant and means to bring this collection to fruition. The final section in this collection is dedicated to recommendations for practices within higher education institutions to further the case the contributors make in ensuring the disabled and chronically ill are included in the academy of the future.

References

- Abouserie, Reda. 'Stress, Coping Strategies and Job Satisfaction in University Academic Staff', *Educational Psychology* 16/1 (1996): 49–56. Online. <https://doi.org/10.1080/0144341960160104> (accessed 19 May 2020).
- Albrecht, Gary L., ed. *Encyclopedia of Disability*. Thousand Oaks, CA: Sage, 2006. Online. <http://dx.doi.org/10.4135/9781412950510> (accessed 19 May 2020).
- Bauman, Zygmunt. *Community: Seeking Safety in an Insecure World*. Cambridge: Polity Press and Malden, MA: Blackwell, 2001.
- Blackmore, Paul. *Prestige in Academic Life: Excellence and Exclusion*. Abingdon and New York: Routledge, 2016.
- Brown, Nicole and Leigh, Jennifer. 'Ableism in Academia: Where are the Disabled and Ill Academics?' *Disability and Society* 33/6 (2018): 985–9. Online. <https://doi.org/10.1080/09687599.2018.1455627> (accessed 19 May 2020).
- Campbell, Fiona Kumari. 'Inciting Legal Fictions: "Disability's" Date with Ontology and the Ableist Body of the Law', *Griffith Law Review* 10/1 (2001): 42–62.
- Campbell, Fiona Kumari. *Contours of Ableism: The Production of Disability and Aabledness*. Basingstoke and New York: Palgrave Macmillan, 2009.
- Department for Business Innovation and Skills. *Students at the Heart of the System*. London: Department for Business Innovation and Skills, 2011. Online. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/31384/11-944-higher-education-students-at-heart-of-system.pdf (accessed 7 September 2016).
- Department for Business Innovation and Skills. *Success as a Knowledge Economy: Teaching Excellence, Social Mobility and Student Choice*. London: Department for Business Innovation and Skills, 2016. Online. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/523396/bis-16-265-success-as-a-knowledge-economy.pdf (accessed 7 September 2016).
- Dolmage, Jay Timothy. *Academic Ableism: Disability and Higher Education*. Ann Arbor: University of Michigan Press, 2017. Online. <https://doi.org/10.3998/mpub.9708722> (accessed 19 May 2020).
- Faulkner, Sandra L. *Poetic Inquiry: Craft, Method and Practice*, 2nd ed. New York: Routledge, 2020.
- Gabriel, Deborah and Tate, Shirley Anne. *Inside the Ivory Tower: Narratives of Women of Colour Surviving and Thriving in British Academia*. London: Trentham Books, 2017.
- Gewirtz, Sharon and Cribb, Alan. 'Representing 30 Years of Higher Education Change: UK Universities and the *Times Higher*', *Journal of Educational Administration and History* 45/1 (2013): 58–83. Online. <https://doi.org/10.1080/00220620.2013.730505> (accessed 19 May 2020).
- Goffman, Erving. *The Presentation of Self in Everyday Life*. London: Penguin Books, 1990, originally 1959.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books, 1990, originally 1963.
- Goodley, D. *Dis/ability Studies: Theorising Disablism and Ableism*. London: Routledge, 2014.
- Harris, Suzy. 'Rethinking Academic Identities in Neo-liberal Times', *Teaching in Higher Education* 10/4 (2005): 421–33. Online. <https://doi.org/10.1080/13562510500238986> (accessed 19 May 2020).
- Henkel, Mary. *Academic Identities and Policy Change in Higher Education*. Higher Education Policy Series 46. London and Philadelphia: Jessica Kingsley, 2000.
- Hussey, Trevor and Smith, Patrick. 'The Trouble with Learning Outcomes', *Active Learning in Higher Education*, 3/3 (2002): 220–33. Online. <https://doi.org/10.1177/1469787402003003003> (accessed 19 May 2020).
- Kerschbaum, Stephanie L., Eisenman, Laura T. and Jones, James M., eds. *Negotiating Disability: Disclosure and Higher Education*. Ann Arbor: University of Michigan Press, 2017. Online. <https://doi.org/10.3998/mpub.9426902> (accessed 19 May 2020).
- Law, David and Hoey, Michael, eds. *Perspectives on the Internationalisation of Higher Education*. Abingdon and New York: Routledge, 2018.
- Leavy, Patricia. *Method Meets Art: Arts-Based Research Practice*, 2nd ed. New York: Guilford Press, 2015.

- Lewis, Magda. 'Public Good or Private Value: A Critique of the Commodification of Knowledge in Higher Education – A Canadian Perspective'. In *Structure and Agency in the Neoliberal University*, edited by Joyce E. Canaan and Wesley Shumar, 65–86. (Routledge Research in Education 15.) Abingdon and New York: Routledge, 2008. Online. <https://doi.org/10.4324/9780203927687> (accessed 19 May 2020).
- Lovin, C. Laura. 'Feelings of Change: Alternative Feminist Professional Trajectories'. In *Feeling Academic in the Neoliberal University: Feminist Flights, Fights and Failures*, edited by Yvette Taylor and Kinneret Lahad, 137–62. (Palgrave Studies in Gender and Education). Cham, Switzerland: Palgrave Macmillan, 2018. Online. https://doi.org/10.1007/978-3-319-64224-6_7 (accessed 19 May 2020).
- Marr, Liz and Forsyth, Rachel. *Identity Crisis: Working in Higher Education in the 21st Century*. Stoke on Trent: Trentham Books, 2011.
- Price, Margaret. *Mad at School: Rhetorics of Mental Disability and Academic Life*. Ann Arbor: University of Michigan Press, 2011. Online. <https://doi.org/10.3998/mpub.1612837> (accessed 27 May 2020).
- Robinson, Wendy and Hilli, Angelique. 'The English "Teaching Excellence Framework" and Professionalising Teaching and Learning in Research-Intensive Universities: An Exploration of Opportunities, Challenges, Rewards and Values from a Recent Empirical Study', *Foro de Educación* 14/21 (2016): 151–65. Online. <https://doi.org/10.14516/fde.2016.014.021.008> (accessed 19 May 2020).
- Taylor, Yvette and Lahad, Kinneret, eds. *Feeling Academic in the Neoliberal University: Feminist Flights, Fights and Failures*. Palgrave Studies in Gender and Education. Cham: Palgrave Macmillan, 2018. Online. <https://doi.org/10.1007/978-3-319-64224-6> (accessed 19 May 2020).
- Thompson, John and Bekhradnia, Bahram. *The Independent Review of Higher Education Funding: An Analysis*. London: Higher Education Policy Institute, 2010. Online. <https://www.hepi.ac.uk/2010/10/15/the-independent-review-of-higher-education-funding-an-analysis/> (accessed 19 May 2020).
- Tilak, Jandhyala B.G. 'Higher Education: A Public Good or a Commodity for Trade?' *Prospects* 38/4 (2008): 449–66. Online. <https://doi.org/10.1007/s11125-009-9093-2> (accessed 19 May 2020).
- Waitere, Hine Jane, Wright, Jeannie, Tremaine, Marianne, Brown, Seth and Pausé, Cat Jeffrey. 'Choosing Whether to Resist or Reinforce the New Managerialism: The Impact of Performance-based Research Funding on Academic Identity', *Higher Education Research and Development* 30/2 (2011): 205–17. Online. <https://doi.org/10.1080/07294360.2010.509760> (accessed 19 May 2020).
- Watermeyer, Richard. 'Lost in the "Third Space": The Impact of Public Engagement in Higher Education on Academic Identity, Research Practice and Career Progression', *European Journal of Higher Education* 5/3 (2015): 331–47. Online. <https://doi.org/10.1080/21568235.2015.1044546> (accessed 19 May 2020).
- Winter, Richard. 'Academic Manager or Managed Academic? Academic Identity Schisms in Higher Education', *Journal of Higher Education Policy and Management* 31/2 (2009): 121–31. Online. <https://doi.org/10.1080/13600800902825835> (accessed 19 May 2020).
- Wolbring, Gregor. 'The Politics of Ableism', *Development* 51/2 (2008): 252–8. Online. <https://doi.org/10.1057/dev.2008.17> (accessed 19 May 2020).
- Wolbring, Gregor. 'Expanding Ableism: Taking Down the Ghettoization of Impact of Disability Studies Scholars', *Societies* 2/3 (2012): 75–83. Online. <https://doi.org/10.3390/soc2030075> (accessed 19 May 2020).