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Title: Ableism in academia: Where are the disabled and ill academics?**Abstract**

Recent coverage in Higher Education newspapers and social media platforms imply that chronic conditions, illnesses and disabilities are becoming more prominent amongst academics. Changes to funding structures, increased globalisation, marketisation and bureaucratisation of Higher Education have resulted in a performance-driven working environment where teaching workload and pressures to publish are further intensified due to excellence exercises in teaching and research (Gewirtz and Cribb, 2013). The result is low morale and an ever-rising number of reported mental health issues, burnout and stress-related illnesses within academia (Darabi et al., 2017). This article explores some of those issues in the context of Higher Education institutions in the UK. We draw on our research and our experiences as speakers regarding ableism in academia to provide food for thought, stimulate a debate and raise awareness of those academics experiencing chronic illness, disability or neurodiversity whose voices are not heard.

Key words:

disability in academia, chronic illness in academia, neurodiversity in academia, ableism in academia, invisible disability, invisible illness, academic ableism

Disabled academics and students

The proportion of staff in universities declaring health conditions or impairments rose from 2.2% in 2003-04 to 3.9% in 2012-13 (HESA, 2017). However, 16% of working age adults (GOV, 2014), and nearly 13% of undergraduates have a known disability (HESA, 2017). Considering these statistics, there is a stark underrepresentation of disabilities, chronic conditions, invisible illnesses and neurodiversity amongst academic staff.

However, at the same time there is increased coverage and interest about disability issues in academia. This may be linked to more awareness and acceptance of disabilities and chronic illnesses, as specific illness experiences are becoming more openly discussed, resulting in increased numbers of 'disclosures'. However, the vast majority of publications relate to students, and making adjustments for students. Naturally, the matter of declaring hidden and invisible disabilities and illnesses is a primary concern. Yet, statistics show that disclosure rates are higher amongst students than staff; and so, our question: "Where are the disabled and ill academics?"

Illnesses, neurodiversity, and disabilities in academia

Depending on one's ontological and epistemological view, disability is either considered as the experience resulting from a biological or medical focus on the personal; or as the experience of social oppression and environmental barriers. Within the binary of the medical versus the social model of disability, impairment or chronic illness focus on the biological and functional, whereas disability reflects the social and environmental response to the biological and functional. We are concerned with a further complication within this existing binary: the role of chronic illness in relation to disability (Oliver, 1996). According to the social model of disability, a disability is socially constructed and is interpreted on a social, environmental level. However, this social, environmental experience may well follow from a physical, biological, and functional cause of disease or chronic illness. Therefore, illness and disability should not be entirely separated, as "pain, fatigue, depression and chronic illness are constant facts for many of us" (Crow, 1996, p.58).

Whilst disabilities, illnesses and neurodiversity are treated differently, with regard to our concern in relation to where those academics are, they can and should be conflated. After all, they are all commonly considered as deviants and divergences from norms. Today's society is particularly focused on standards, norms, league tables, achievements and productivity. As a result, ableism is internalised, normalised and ingrained to such an extent that being "normal or non-disabled" is no longer sufficient. Indeed, transhumanist hyper-normative enhancement is becoming a new normal (Goodley, 2014, p.25).

"Disclosure" in academia

Disclosure is understood in connection with "disclosing" something that people are ashamed of, keep secret and then feel obliged to open up about. If we reject ableism then we should be comfortable with illness or disability, and so should not feel the need to "disclose". Academia, though, prides itself for research activity, teaching excellence, knowledge exchanges and transfers. In this working environment overwork is normalised. Scholarly contributions and institutional citizenship are so prized that holidays and sick leave are minimised, if not avoided. Therefore, people feel they cannot be honest about their issues or health concerns and keep them secret.

Declaring a disability, chronic illness or neurodiversity is not only a matter of succumbing to social oppression and control. Ticking the "I am disabled" box is a statement and commitment. By underwriting a disability, the academic has to be confident and comfortable with identifying as a disabled person. Illness and disability trajectories are often experienced as journeys of acceptance, particularly if these illnesses or disabilities occur later in life or appear suddenly. To be confident enough to tick the "I am disabled" box means that this person would have accepted his/her dysfunction, disability or illness. This might mean learning to accept chronic illness, neurodiversity or disability as a normal experience of life or even as an asset, an outlook on disability that is at odds with internalised ableism. In addition to this very personal interpretation and understanding of disability, a public disclosure brings further risks. Academics, specifically early-career academics, worry about the consequences of being identified as someone dealing with health issues and

conditions. In an environment where temporary, as-and-when contracts are more prevalent than permanent, tenured positions, employees are concerned about job insecurity. Individuals fear that by admitting to health conditions or disabilities they may be worsening their chances for employment.

Whether or not academics choose to disclose their disabilities and illnesses is, in practice, a risk-benefit analysis of consequences associated with the specific concern or issue. In order to access support, workplace adjustments, potential financial benefits and allowances, academics do need to disclose their conditions. However, disclosing could potentially mean being categorised as a non-deviant within the normed and normalised society, which in turn leads to being stigmatised (Goffman, 1990a). Within academia it is this stigmatisation that causes particular concerns. Invisible, less known or contested conditions are dismissed as a fabrication, malingering, and as an act of a fundamentally lazy or overwhelmed worker seeking validation. Considering such strong views, the act of disclosing automatically links the personal and private to the public.

The decision about whether to disclose or to hide a condition is therefore an act of self-preservation, information control and impression management (Goffman, 1990a; Goffman, 1990b), thus identity work. So how is academic identity impacted if an academic makes adjustments to work-life arrangements, has to limit work to a part-time position, or has to work differently due to illness or disability?

Disability, illness and academic identity

In our research projects about academic identity, we ask academics to reflect on the impact chronic and temporary illnesses or disabilities may have. These research projects are reported elsewhere (Brown, 2017; Brown, 2018; Brown and Leigh, forthcoming; Leigh, forthcoming a; Leigh forthcoming b), but suffice it to say that “the emotional ties to academic labour are binding” (Chubb et al., 2017, p. 556). Academics with disabilities or illnesses work hard to hold onto their academic work and identity whilst compromising other aspects of their life. In contrast, non-academic individuals with similar health challenges reported that work was the first thing they dropped to maintain their personal lives and relationships.

Academics with health conditions are concerned that they are not taken seriously or seen as academics in their own right, and that their achievements and publications are considered through the lens of their disability status. Though this can in turn lead to successful careers within critical disability studies, this may not be their disciplinary passion or desired career focus. They may be expected to trade off their identity. They fear that they are suddenly no longer seen as academics or persons, but as their disability or health condition. In this sense, academics themselves are the physical manifestation of internalised ableism within academia.

Ableism in academia

Moving in the circles of ableism studies and disability research we have witnessed the increased calls for making conferences and/or studies more accessible and equitable. We have witnessed how a support group for disabled women in academia gained more than 60 members in less than 24 hours. We have witnessed how an event about ableism in academia attracted so much attention that four separate institutions provided funding, that all 80 tickets were allocated with more than 70 people on a waiting list. Ableism in academia is endemic and so the concern for equality and equitability is on the increase. But there still remains our question: where are all the academics with disabilities, chronic illnesses or neurodiversity? Particularly, given the comparatively high number of student disclosures, according to which 11.5% of postgraduate research students have a known disability (HESA, 2017)?

Of course, not every student who graduates seeks a career within academia, but there is a pipeline. So, what happens to those that have disclosed their conditions and issues as students once they have graduated? Do they experience academia as an ableist community and so simply leave the academy? If not, when and why do those with disabilities and illnesses stop disclosing? How do they reconcile their past as disabled or ill students with their performed present as able-bodied and able-minded academics? What about those who develop illnesses or acquire disabilities whilst in post? Where does this leave the academy and what can be done?

A societal shift in relation to our understanding of disabilities is needed. Rather than focusing on disabilities and illnesses, it is time to consider how ingrained the normalisations are in society that we all aspire to. Being human in this ableist community or society is not merely being, but being perfect and meeting specific criteria, “a particular kind of self and body (the corporeal standard)” (Kumari Campbell, 2009, p. 5). Becoming more consciously aware of how we measure and compare our bodies and selves to such standards is a first step, but also raising awareness through conferences and articles. In the long-term, academics need to be seen not as the privileged elite sitting in the ivory tower of scholarship, but as individuals who, when it comes to navigating workplaces, may also be marginalised and whose voices may remain equally unheard. We trust this article will contribute to changing that situation, so that their voices can be heard more loudly in the future.

References:

- Brown, N. (2017). The construction of academic identity under the influence of fibromyalgia. In: Henderson, H., Pennant, A. L., & Hand, M. (eds.). *Papers from the Education Doctoral Research Conference Saturday 26 November 2016. School of Education*. Birmingham: University of Birmingham. pp. 18-25.
- Brown, N. (2018). Video-conference interviews: Ethical and methodological concerns in the context of health research. *SAGE Research Methods Cases*. <http://dx.doi.org/10.4135/9781526441812>
- Brown, N., & Leigh, J. (forthcoming). Creativity and playfulness in Higher Education research. *Theory and Method in Higher Education Research*.
- Chubb, J., Watermeyer, R., & Wakeling, P. (2017). Fear and loathing in the academy? The role of emotion in response to an impact agenda in the UK and Australia. *Higher Education Research and Development*. 36(3):556-568.
- Crow, L. (1996). Including all of our lives: renewing the social model of disability. In: Barnes, C., & Mercer, G. (eds.). *Exploring the Divide: Illness and Disability*. Leeds: Disability Press, pp. 55-73.
- Darabi, M., Macaskill, A., & Reidy, L. (2017). Stress among UK academics: identifying who copes best. *Journal of Further and Higher Education*, 1(3):393-412.
- Gewirtz, S., & Cribb, A. (2013). Representing 30 years of higher education change: UK universities and the Times Higher. *Journal of Educational Administration and History*, 45(1):58-83.
- Goffman, E. (1990a). *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books.
- Goffman, E. (1990b). *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Goodley, D. (2014). *Dis/Ability Studies: Theorising Disablism and Ableism*. Abingdon: Routledge.
- GOV (2014). <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures> accessed 03/1/2017
- HESA (2017). <https://www.hesa.ac.uk/data-and-analysis> accessed 03/11/2017.
- Kumari Campbell, F. (2009). *Contours of Ableism: The Production of Disability and Aabledness*. Basingstoke: Palgrave Macmillan.
- Leigh, J. (forthcoming a). An embodied approach in a cognitive discipline. In: Breeze, M., Costa, C. & Taylor, Y. (eds.) *Time and space in the neo-liberal university: Futures and fractures in higher education*. Basingstoke: Palgrave Macmillan.
- Leigh, J. (forthcoming b). Embodied practice an embodied academic identity. In: Leigh, J. (ed) *Conversations on embodiment: Teaching, research, and practice*. Abingdon: Routledge.
- Oliver, M. (1996). Defining impairment and disability: issues at stake. In: Barnes, C., & Mercer, G. (eds.). *Exploring the Divide: Illness and Disability*. Leeds: Disability Press, pp. 39-54.