Kent Academic Repository
Full text document (pdf)

Citation for published version

DOI

Link to record in KAR

http://kar.kent.ac.uk/66490/

Document Version

Author's Accepted Manuscript

Authors: Nicole Brown and Jennifer Leigh

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

Introduction:

Recent coverage in relevant Higher Education newspapers and corresponding social media platforms, imply that chronic conditions, illnesses and disabilities are becoming more prominent amongst academics. Changes to funding structures (Thompson and Bekhradnia, 2010), increased globalisation, marketisation and bureaucratisation of Higher Education (Tilak, 2008; Gewirtz and Cribb, 2013) 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. The result is low morale (Sutton, 2017) and an ever-rising number of reported mental health issues, burnout and stress-related illnesses within academia (Abouserie, 1996; Taris et al., 2001; Opstrup and Pihl-Thingvad, 2016; Darabi et al., 2017). To an extent, this heightened coverage and interest is linked to an increased awareness, acceptance and tolerance of disabilities and chronic illnesses within society in general, and the Higher Education sector in particular. Specific illness experiences are becoming more openly discussed, which results in increased numbers of disclosures. The proportion of staff in universities disclosing conditions or impairments rose from 2.2% in 2003-04 to 3.9% in 2012-13 (HESA, 2017). However, according to government demographics 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.

There is a large body of research and literature available regarding the experiences of the disabled, neurodiverse and chronically ill in Higher Education. However, the vast majority of publications relate to students, and making adjustments for students to enable them to study and support their learning, which is nowadays commonplace for universities (Leake and Stodden, 2014). Naturally, the matter of disclosure is still an issue for students, with hidden and invisible disabilities and illnesses a primary concern (Riddell and Weedon, 2014; Clouder et al., 2016). There are also considerations of the extent of disclosure for physically disabled students, who may be unwilling to disclose the extent to which the secondary effects of their condition affect them (Hannam-Swain, 2018). Yet, evidence and statistics show that disclosure rates are higher amongst students than staff; and thus, our question: "Where are the disabled and ill academics?".

In this article, we draw on our research relating to academic identity and on 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.

Illnesses, neurodiversity, and disabilities in academia

Before offering the context of disclosure issues within academia, the content of what is to be disclosed is worth considering. 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 (Fawcett, 2000). 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. Taking into account sociological approaches, illness and disability cannot and indeed should not be entirely separated, as "pain, fatigue, depression and chronic illness are constant facts for many of us" (Crow, 1996, p.58). In a similar vein, the experience of neurodiversity can be equally tiring and depressing.

Whilst disabilities, illnesses and neurodiversity are of course treated differently, with regard to our concern in relation to the question of where those academics are, these issues can and should be conflated. This is because in a society that is performance-driven and focussed on standards, norms, league tables, achievements and productivity; disability, chronic illness and neurodiversity are divergences from that norm. In fact, ableism is so internalised, normalised and ingrained that "the richest global citizens are no longer interested in being normal or non-disabled" (Goodley, 2014, p.25), and they are looking for transhumanist hyper-normative enhancement.

Disclosure issues in academia

As outlined at the beginning of this article, the social environment of academia is characterised by performance and productivity. In effect, academia prides itself for research activity, teaching excellence, knowledge exchanges and transfers. In this working environment it is not uncommon to put in a nightshift to complete grant applications or final revisions for publications. Scholarly contributions and institutional citizenship are prized to such an extent that holidays and sick leave are minimised, and at best avoided altogether. Academic identity is directly equated with academic work (Neary and Winn, 2016) or a lifestyle choice. It is therefore not surprising that in such an oppressive environment, people feel they cannot disclose their issues or health concerns.

However, disclosing a disability, chronic illness or neurodiversity, or not, is not only a matter of succumbing to social oppression and control. Ticking the "I am disabled" box needs to be considered as 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 characterised by and experienced as journeys of acceptance, particularly so if these illnesses or disabilities occur later in life or appear suddenly. For an academic to be confident enough to tick the "I am disabled" box means that this person would have had to accept his/her dysfunction, disability

or illness, a process that is likened to the stages of grieving (Telford et al., 2006). Coming to terms with a newly diagnosed disability, chronic illness or neurodiversity would therefore mean learning to accept disability as a normal experience of life or even as an asset. Individuals need to learn that disability or illness is not necessarily something that we need to cope with. This represents a coming to terms with the societal ableist attitude that would have been internalised for an entire lifetime. 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 (Blix et al., 1994; Tytherleigh et al., 2005; Watts and Robertson, 2011). Individuals fear that by admitting to health conditions or disabilities they may be worsening their chances for employment, and therefore decide to cover up and hide their issues. On application forms for jobs, promotion and research grants applicants are advised to specify any constraints they might have to perform the role, and yet, they are told they do not have to disclose any disability. Rather than reassuring disabled academics and alleviating any potential fears, these quite conflicting messages actually reinforce people's inherent insecurity.

Whether or not academics choose to disclose their disabilities and illnesses, is connected with the visibility of their conditions, and also with the general acceptability and status of the conditions in the context in which they work. In practice, each individual has to undertake a risk-benefit analysis of consequences associated with the disclosure of his/her 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 should cause particular concerns, as 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 to disclose or 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? Do these individuals lose their academic identity?

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 our findings echo those of Chubb et al. (2017) who state that "the emotional

ties to academic labour are binding" (p. 556). Academics with disabilities or illnesses consciously work hard to hold onto and safeguard their academic work and identity whilst compromising other aspects of their life such as social time, family and friends. In contrast, non-academic individuals who face similar health challenges reported that work was the first thing they dropped to maintain their personal lives and relationships.

In our experiences 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 not seen as just that, but 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 the disciplinary passion or desired career focus for the individual. They worry that they are pigeon-holed as the people who need to be treated sympathetically, with pity, who are not capable enough for leadership opportunities or advancement. 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 that was scheduled for 40 participants attracted so much attention that there are now 80 tickets sold and more than 70 potential attendees on a waiting list and funding from four separate institutions. Ableism in academia is endemic and so the concern for equality and equitability is on the increase. But where then 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? Why do academics succumb to ableism? And what consequences does this enforced performativity and information control around their identity have? 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 focussing 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)" (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, such as one the authors are currently planning, and articles like this. 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.

References:

Abouserie, R. (1996). Stress, coping strategies and job satisfaction in university academic staff. *Educational Psychology*, *16*(1):49-56.

Blix, A., Cruise, R., Mitchell, B., & Blix, G. (1994). Occupational stress among university teachers. *Educational Research*, *36*(2):157-169.

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., & Leigh, J. (forthcoming). Creativity and playfulness in Higher Education research. *Theory and Method in Higher Education Research.*

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

Campbell, F. (2009). *Contours of Ableism: The Production of Disability and Abledness*. Basingstoke: Palgrave Macmillan.

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.

Clouder, L., Adefila, A., Jackson, C., Opie, J., & Odedra, S. (2016). The discourse of disability in higher education: insights from a health and social care perspective. *International Journal of Educational Research*, *79*:10-20.

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.

Fawcett, B. (2000). *Feminist Perspectives on Disability*. Harlow, England: Pearson Education.

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

Hannam-Swain, S. (2018). The additional labour of a disabled PhD student. *Disability and Society*, 33(1):138-142.

HESA (2017). https://www.hesa.ac.uk/data-and-analysis accessed 03/11/2017.

Leake, D., & Stodden, R. (2014). Higher education and disability: Past and future of underrepresented populations. *Journal of Postsecondary Education and Disability*, *27*(4):399-408.

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.

Neary, M., & Winn, J. (2016) Against academic identity. *Higher Education Research and Development.* 35(2):409-412.

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.

Opstrup, N., & Pihl-Thingvad, S. (2016). Stressing academia? Stress-as-offence-to-self at Danish universities. *Journal of Higher Education Policy and Management*, *38*(1):39-52.

Riddell, S., & Weedon, E. (2014). Disabled students in higher education: Discourses of disability and the negotiation of identity. *International Journal of Educational Research*, *63*:38-46.

Sutton, P. (2017). Lost souls? The demoralization of academic labour in the measured university. *Higher Education Research and Development* 36(3)625-636.

Taris, T., Schreurs, P., & Van Iersel-Van Silfhout, I. (2001). Job stress, job strain, and psychological withdrawal among Dutch university staff: towards a dual process model for the effects of occupational stress. *Work and Stress*, *15*(4):283-296.

Telford, K., Kralik, D., & Koch, T. (2006). Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing*, *55*(4):457-464.

Thompson, J., & Bekhradnia, B. (2010). *The Independent Review of Higher Education Funding: An Analysis*. London: Higher Education Policy Institute.

Tilak, J. (2008). Higher education: a public good or a commodity for trade? *Prospects*, 38(4):449-466.

Tytherleigh, M., Webb, C., Cooper, C., & Ricketts, C. (2005). Occupational stress in UK higher education institutions: A comparative study of all staff categories. *Higher Education Research and Development*, *24*(1):41-61.

Watts, J., & Robertson, N. (2011). Burnout in university teaching staff: a systematic literature review. *Educational Research*, *53*(1):33-50.