

Disclosure dances: The experience of PhD students with invisible disabilities in higher education

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Overview

Context and background to research

Introduction to Embodied Inquiry

Findings

Recommendations for practice

What does it feel like to be disabled/chronically ill/neurodivergent in academia?

Defining "disability", in relation to "impairment"

"not disabled enough"

Context of academia as working environment

Disability in academia

3.9% of UK HE staff disclosed a health condition or impairment in 2012/13, but at the time, 16% of working-age adults and 13% of undergraduate students were known to have disability.

14.4% of disclosures in UK HE in 2017/18 were undergraduate students, compared to 9.3% of taught postgraduate students and 9.0% of postgraduate research students.

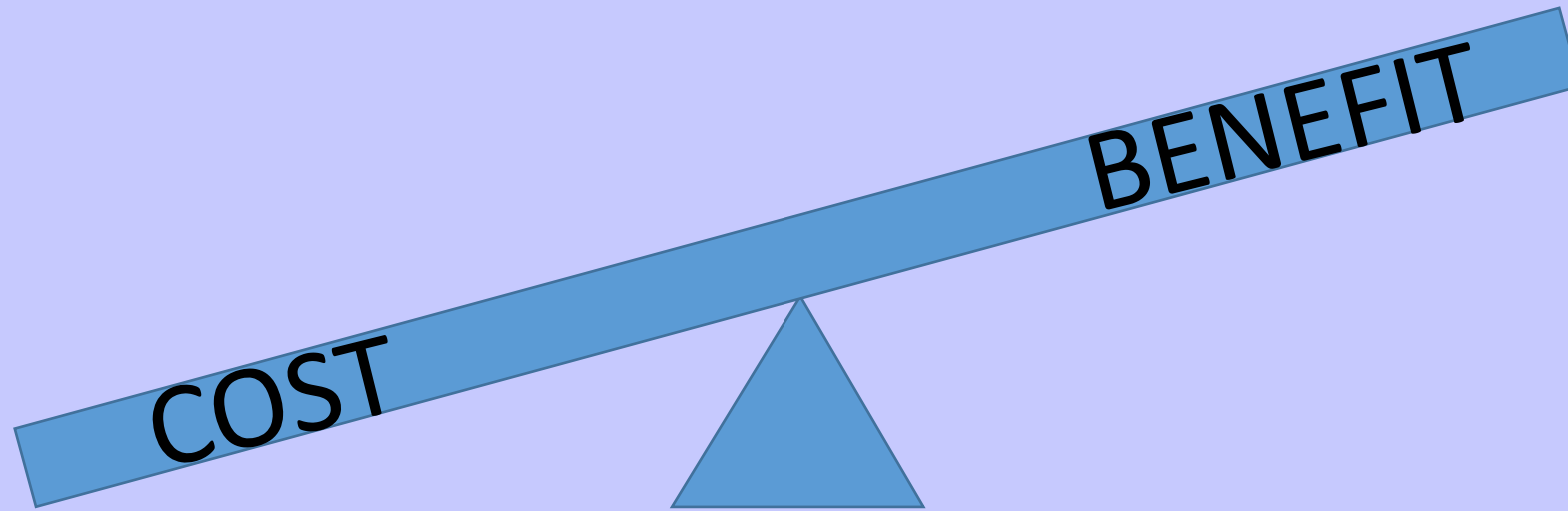
Overall disclosure rates (5.3%) lower among academic staff (4.3%) than professional services and support staff (6.1%):

- 5.3% teaching-only academics

- 4.2% teaching and research academics

- 3.2% research-only academics.

Disclosure is a cost-benefit analysis



Brown, N. (2020). Disclosure in academia: A sensitive issue. In: Brown, N., & Leigh, J. (eds.). *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. London: UCL Press, 226-236.

Introduction of Embodied Inquiry

focus on bodily and embodied experiences

lived experiences, the researcher's body in the field, the body as a communicator and the body in interaction

theoretical foundations in phenomenology and hermeneutics

cornerstones of human understanding/communication

human understanding is embodied, language is insufficient and inexact, communication and understanding are metaphorical

Data in Embodied Inquiry

Embodied Inquiry sees knowledge as produced and relational, contextual, multimodal and the researcher as a data traveller

Process:

- Visual representation of experience in higher education
- Conversation

Participants

Recruited via social media to opt-in

12 participants (10:2), 1 person dropped out

Wide range of disabilities:

one wheelchair user, one participant using a white cane; 3 participants with one or several neurodiversities: autism, Asperger's syndrome, dyslexia, dyspraxia and attention deficit and hyperactivity disorder (ADHD); several participants have diagnoses related to mental health issues, such as depression and bipolar disorder, either on their own or in conjunction with the psychosomatic condition fibromyalgia; other conditions and disabilities mentioned were narcolepsy, asthma, chronic migraine, cystitis, irritable bowel syndrome, postural tachycardia syndrome (POTS) and traumatic brain injury following an accident; PLUS: fatigue, sensory overload, headaches and nausea







Analysis

Thematic Analysis (Braun and Clarke, 2006, 2019)

- iterative

- inductive

- semantic

- reflexive

Exploratory, creative analysis in line with Embodied Inquiry

Findings

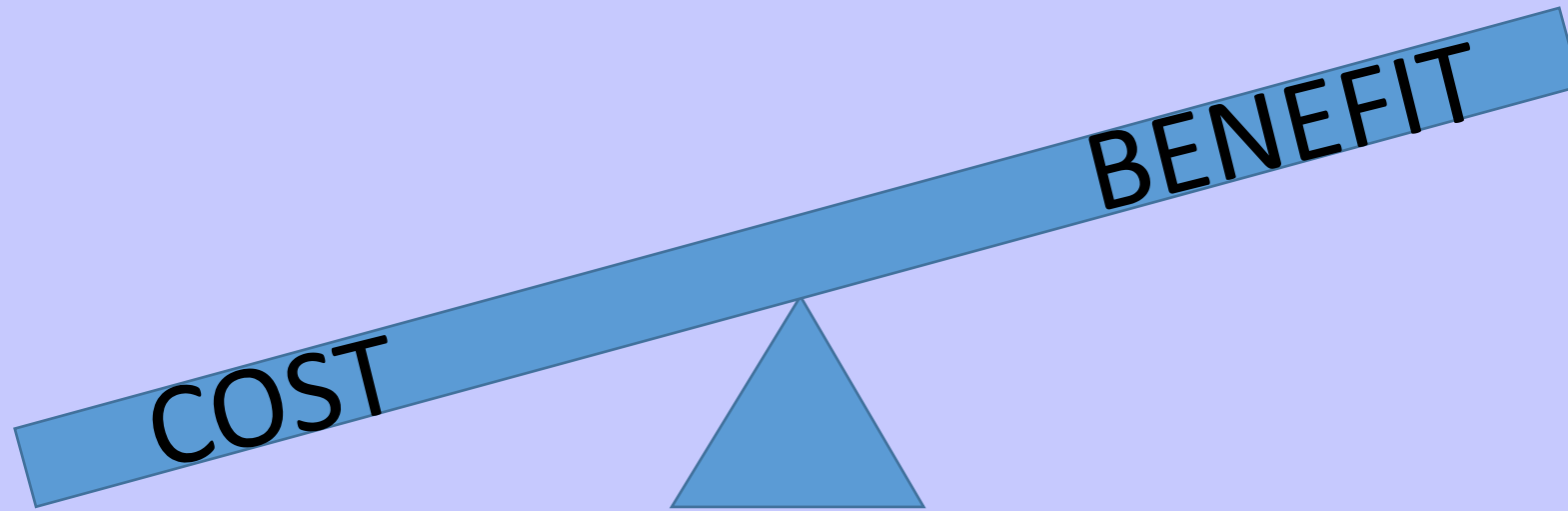
Management of the buildings

nowhere to rest, scents and smells, staircases

Consideration about career – adjustments not helpful

Disclosing with immediate supervisor, but nobody else

Disclosure is a cost-benefit analysis



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Recommendations for practice

Challenging our own assumptions

Involving individuals in processes and decisions

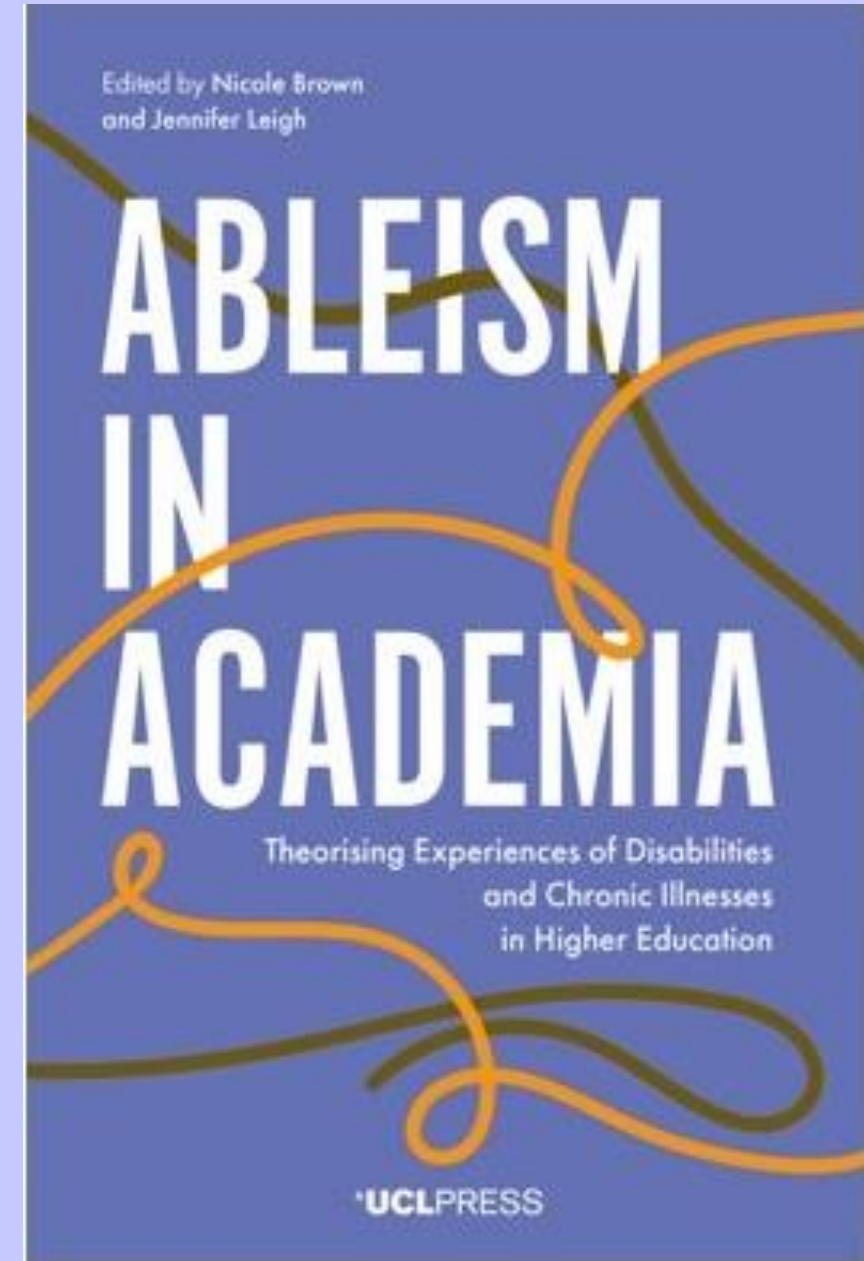
e.g. moving tables/desks

Sharing our own struggles

<https://www.uclpress.co.uk/products/123203>

Ableism in Academia provides an interdisciplinary outlook on ableism that is currently missing. Through reporting research data and exploring personal experiences, the contributors theorise and conceptualise what it means to be/work outside the stereotypical norm.

The volume brings together a range of perspectives, including feminism, post-structuralism, crip theory and disability theory, and draws on the width and breadth of a number of related disciplines. Contributors use technicism, leadership, social justice theories and theories of embodiment to raise awareness and increase understanding of the marginalised.

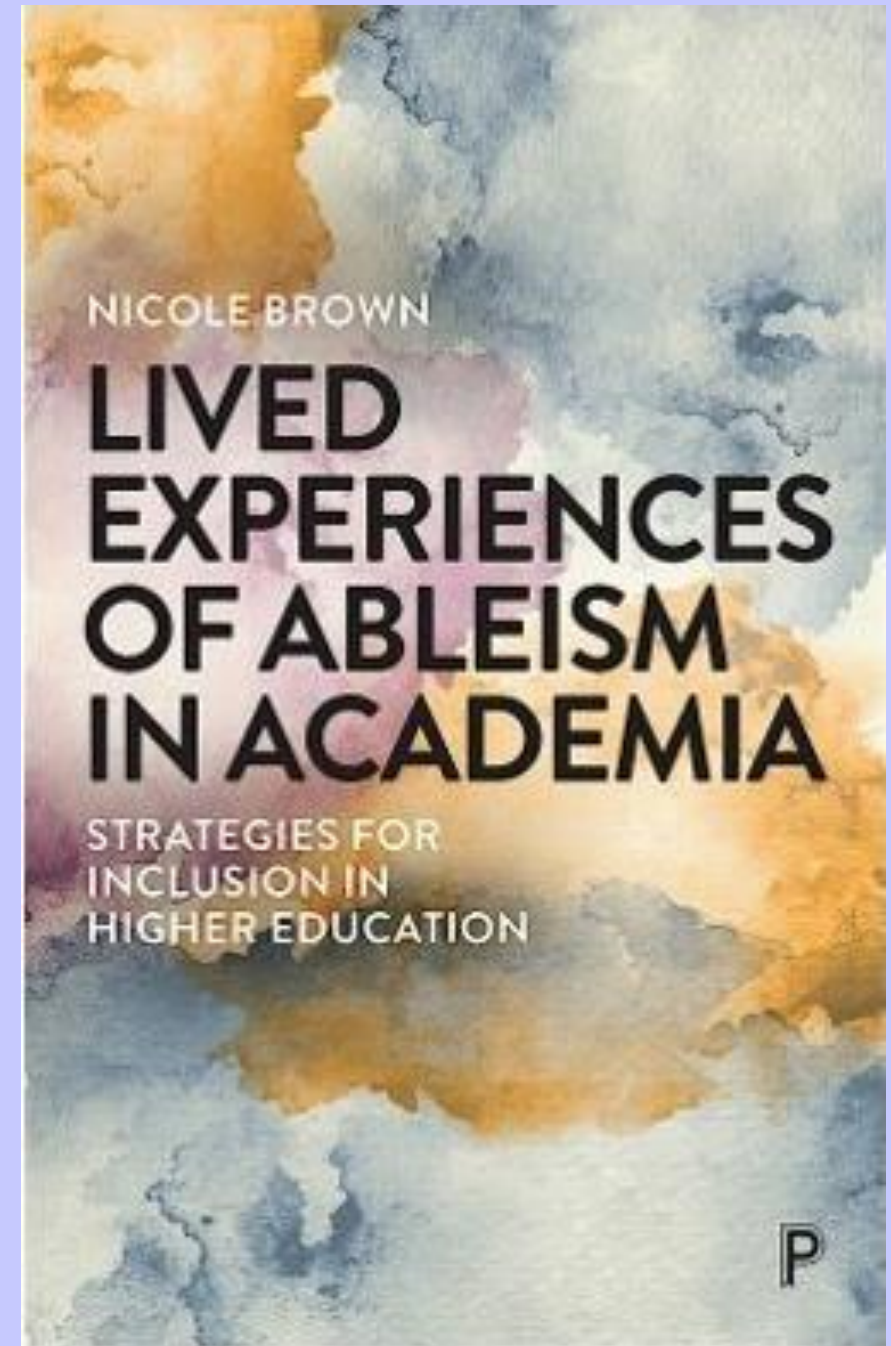


<https://policy.bristoluniversitypress.co.uk/lived-experiences-of-ableism-in-academia>

Demands for excellence and efficiency have created an ableist culture in academia. What impact do these expectations have on disabled, chronically ill and neurodiverse colleagues?

This important and eye-opening collection explores ableism in academia from the viewpoint of academics' personal and professional experiences and scholarship. Through the theoretical lenses of autobiography, autoethnography, embodiment, body work and emotional labour, contributors present insightful, critical, analytical and rigorous explorations of being 'othered' in academia.

Deeply embedded in personal experiences, this perceptive book provides examples for universities to develop inclusive practices, accessible working and learning conditions and a less ableist environment.



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