Ableism in Academia

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Concluding thoughts: Moving forward

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Contrary to academic writing conventions, we do not start this final chapter with a synthesis of ideas from all the contributions. We will come to that; the space afforded here allows us to take a step back and reflect on the entire process of editing this collection. As outlined in the preface, this book originally came about in relation to and conjunction with the ‘Ableism in Academia’ conference that was held at the UCL Institute of Education in March 2018. Some contributors in this book featured in the conference, others attended but did not present and others again were not involved with the conference at all.

What we had not anticipated and therefore had not been prepared for was the reality of bringing together this edited book. While we wanted to represent a diverse and international range of contributions, the impetus from the conference means that the focus of the volume is primarily on the UK and the West. Ableism is not a construct that only occurs in these contexts, and it is easy to imagine that had we been able to include a more international focus that included perspectives from the Global South we would have encountered differing perspectives. In the West it is difficult to admit, as an academic, to being ‘weak’ or ‘ill’. In the Global South, ableism and disability appear to be more prominent as an issue, with a need to hide perceived ‘faults’. While we tried to address this deficit, through contacting people in the field who were generally positive about the need for such a book, none were able or willing to contribute directly to this volume within our short timeframe.

Most editorial teams comment on the difficulty of chasing contributions, shifting deadlines and last-minute scrambles. In the case of this book, there was the added pressure of working with contributors who
identified as chronically ill, disabled and/or neurodiverse. The editorial reality was one of keeping track of emails and draft submissions that were delayed due to illness flare-ups or aggravations of symptoms resulting from individuals balancing work pressures with family commitments in addition to their ill health. Additionally, there were people who would have wanted to contribute, but then felt they could not expose themselves for personal or professional reasons. There were also colleagues who had started a chapter, but then withdrew because they felt they could not produce their chapters in the given timeframe. These changes mean that the final volume has chapters from only women authors, which has inevitably had implications for the content.

At the same time, emails are often not the most conducive way to communicate, and so misunderstandings occurred, between ourselves as editors, particularly in the last few stress-filled days, and between us and our contributors. We would like to unreservedly apologise for any words that were written too tersely or quickly. We are grateful for the support we have had from our editor at UCL Press, who was forgiving and accommodating. The reality remains, though, that fluctuating disabilities and illnesses put extra demands on contributors. In everyday experiences of dealing with symptoms of disabilities and illnesses, advocating for one’s rights while continuing to manage work and family commitments, additional tasks, such as a contribution to an edited book, are often the first to be moved down in one’s priority list. A huge part of the process was therefore managing expectations and navigating emotions, our own and each other’s. As a consequence, as editors we worked with shorter timeframes than we would have wished for, which in turn resulted in ever-tighter turnaround times for final changes and submissions that still had to adhere to a fixed publishing timescale within the final few months of the UK Research Excellence Framework (REF) deadline. These pressures were felt by our contributors and by us as editors (for example see chapter 10 on internalised ableism). Ultimately, the practical reality of putting together this edited book is an accurate representation of what ableism in academia is and feels like. The trends towards productivity and efficiency so strongly linked with the neoliberal academy of the twenty-first century, and the tensions that this creates in all academics, but particularly those with disabilities, chronic illnesses or neurodiversity, was played out in the preparation of this manuscript.

The chapters collected here bring together a range of theoretical perspectives that include feminism, poststructuralism (such as Derridean and Foucauldian theory), crip theory and disability theory. They use technicism, leadership and theories of social justice and embodiment...
in order to raise awareness and increase understanding of the marginalised – that is, those academics who are not perfect. They place these theories in the context of neoliberal academia, which is far away from the privileged and romanticised versions that exist in the public and internalised imaginations of academics, and use those theories to interrogate aspects of identity and of how disability is performed, and to explore how and why, as Campbell states in her chapter, ableism is not just a disability issue.

Many of the chapters take a very personal, reflective perspective in order to translate experience into theory, as seen in the poetic contributions from Spaeth, Rode and Jindal-Snape, and chapters by Campbell, Andrews, Finesilver, Rummery and Griffiths as well as those written by us. Some authors specifically focused on autoethnographic perspectives and using this particular methodological approach to constructing and creating knowledge and sharing experience, such as Griffiths, Rummery, Finesilver, Leigh and Brown. These chapters did not tackle the same topics, and yet have been placed and paired so that they complement each other. For example, where Leigh and Brown consider aspects of the personal and political nature of internalised ableism using an embodied approach, perfectionism, pain and wellbeing, Rummery also uses autoethnography to explore how the personal journey and experiences lead to political engagement and activism, and the barriers faced therein by someone with a disability. The activism that both these chapters describe also features in Andrews’ chapter on the autoimmune, and the invisible nature of disability. She draws on Derrida to demonstrate how the cycle of needing to do harder work (to prove oneself) leads to more destruction (physical ill health), which in turn results in less work. She challenges the norms of academia and uses her own lived experience with an autoimmune condition to create theory around ableism. Similarly, Campbell’s chapter on technicism explores ableism in the context of the law, and shapes her theory from her own and others’ lived experiences. She considers the meaning of discrimination and humiliation.

Humiliation can be considered close to paranoia, in that we become paranoid in part because we fear humiliation (among other degradations) and concern over how we are perceived by others. Aspects of paranoia occur in Rode and Snape’s poems as well as Andrews’ chapter and those by Leigh and Brown, Finesilver et al. and Peruzzo. Peruzzo’s voice is unique in this book, as she explores being an outsider in disability research, and the validity and personal experience of someone who does not claim or disclose a disability being engaged in the discourse. She asks us to consider who should be talking about these issues, who should be
involved in the conversation, and takes a poststructuralist approach to consider the power and dominance and need for necessary critique from that outside perspective. These are poignant thoughts when considered from a social justice angle privileging lived experience over theoretical knowledge. In contrast, and placed alongside, Griffiths uses autoethnography to explore the insider status of a disability researcher, the complexities of invisible disability, and considers how this impacts on disclosure in academia, reflecting on her experiences in law practice.

Brown also explores the idea of disclosure in her chapter, drawing on research with academics with fibromyalgia, and her chapter, along with Martin’s, are the only two that use ‘research data’ in the conventional sense in their work. Brown reflects on her positionality, and the impact of disclosure and language on her research participants and herself. Gillberg approaches the idea of disclosure differently, as she hones in on the ideas of the construction and gatekeeping of knowledge, social justice, activism and participation within the academy from a feminist perspective. Feminism is a motif that appears through several other chapters in this book, as it figures significantly in the development of critical theory and the validity placed on lived experiences in higher education.

The last thread woven throughout this volume is that around embodiment. While it is central to some chapters (such as Leigh and Brown, and Finesilver et al.), as might be expected given the nature of our research interests and background, embodiment also appears in many other chapters. Campbell explores the idea of ‘soma-epistemology’, while Andrews, Griffiths and Peruzzo also refer to various aspects and understandings of embodiment, including sociological and anthropological theories. This is important to note, as it demonstrates that scholars from diverse disciplines recognise that ableism, illness and disability are experienced with and through the body, and from these experiences we construct and understand theory. This volume as a whole fills in a gap between the lived experiences of those with chronic illness, disability and neurodiversity in academia.

What the collection shows is that, despite the emotive and sometimes bleak picture that is being painted throughout all these contributions as they discuss humiliation, pain or the personal journey towards disclosure, for example, there is still hope. In their unique ways, whether that is as a poetic expression or as a report on an empirical study, as an autoethnography or philosophical position paper, all contributors seek to educate, to raise awareness and to advocate, despite the potential detriments to their career and/or health and wellbeing. In this sense,
the book is a reflective but forward-looking project that draws on the personal, experienced past in order to show the public present and to focus toward the future.

Ableism in higher education: What next?

As a sector, higher education has seen drastic changes over recent decades, with an increasing emphasis on equality and inclusion (Kerschbaum et al. 2017; Dolmage 2017; Price 2011). Initiatives such as Athena SWAN and the Race Equality Charter have led to more awareness of exclusionary practices, and there is a need to be clear on the policies for the REF and the Teaching Excellence Framework. The sector has become aware of concerns around the health and wellbeing of students and staff. Institutions are responding to these changes, and yet their responses are often fragmented and not well coordinated.

Statistics highlight serious issues in relation to disclosure rates: 16 per cent of the working age public disclose a disability, neurodivergence or chronic illness, but less than 4 per cent of academics working in higher education do so (see Brown and Leigh 2018). In many cases institutions do not know how to respond to staff needs when they are disclosed. The current reactive approach to equality, diversity and inclusion across the sector means that high-quality researchers, academics and professional staff are unable to engage to the best of their abilities and/or do not apply for open positions.

What is required instead, is an active approach to bring about change in research approaches and at policy level, which will ultimately lead to attitudinal changes. Higher education as a research field is in itself complicated. Many researchers come into the field from their specific disciplinary backgrounds, which leads to higher education research being fragmented (Harland 2012; Tight 2014) rather than unified (Brown and Leigh 2019). In addition, the emphasis of research lies on student experience, learning or developing teaching practices (Tight 2004). It is only recently that research on staff experience has gained traction, not least due to the significant changes in contractual conditions and precarious working environments of scholars in today’s globalised, marketised academy (e.g. Mark and Smith 2012; Opstrup and Pihl-Thingvad 2016; Darabi et al. 2017), although initial reports relating to stress in academia were already available in the 1990s (e.g. Abouserie 1996; Blix et al. 1994). Yet within that focus on academic and professional staff within the higher education sector, particular topics
still remain unexplored, of which the experience of disabilities, chronic illnesses and/or neurodiversity is one. A more strategic and systematic approach to these lived experiences within academia would be very welcome, and is much needed, as the interest in the original conference and the edited book have shown, too.

A strengthened focus on and reinforced interest in the experience of disabilities, chronic illnesses and/or neurodiversity in higher education need to take account of several considerations. In line with the disjointed higher education research field, and as this book shows, nobody – irrespective of whether or not they are disabled, chronically ill and/or neurodiverse, or which disciplinary background they are from – should be excluded from theorising their experiences, but should be encouraged to add new perspectives to the field. It is all too easy to dismiss experiences as imagined or ‘in your head’; the reality remains that even if discrimination and ableist attitudes are not intentional, they are felt. For some scholars, disability studies as a field provides the much-needed theorisation of the disabled experience; but not everyone will identify with the field equally strongly and may struggle to come to terms with disability, illness and/or neurodivergence on a personal level. Again, such experiences must be taken seriously, accepted and used to inform policy and practice. This is where an attitudinal change is key. Unfortunately, change generally takes time, but attitudinal shifts often mean that resistance to change needs to be overcome (Eagly and Chaiken 2014). In relation to disabilities, attitudinal changes tend to happen through specific interventions, such as the reduction of discomfort experienced by non-disabled persons, presenting non-disabled communities with relevant information and fostering empathy (Donaldson 1980). Systematic research, autoethnographically inspired investigations, books and articles need to become more prominent (see for example Brown forthcoming), as there are many gaps that even this book has not been able to fill.

As a first step in the right direction, we would like to share the knowledge we have gained through the lightning talks and the workshop at the conference, the synchronous and asynchronous discussions related to the conference, and the formal and informal conversations we have had with colleagues as a result of the conference and our publications, as well as through the contributions on hand. We also draw on the results from three different research projects over the course of the last three years, along with ongoing work in our own and other institutions to shed light on ableism in academia. We used these to compile a practical document that shares causes for concern within academia before presenting some recommendations for practical implementations in higher education.
institutions. The delegates from the ‘Ableism in Academia’ event wanted exactly this type of practical document to take back to their own institutions, and so it is another direct result from the conference. It is more than a manifesto. It does not simply list what we want; instead it sets out in clear, business terms the risks to a university when it does not address ableism, and then gives clear, achievable recommendations to challenge the status quo, and to enact change.

Causes for concern in higher education institutions

Staff support

Student support is often well developed and easily accessible, whereas staff support is often separate, or linked to cumbersome access-to-work assessments with a smaller budget. In some universities staff register as students to be able to access adjustments, resources and support that is otherwise unavailable. This normalises the assumption that academic staff are able-bodied. The kinds of conditions that might require support include specific learning disabilities such as dyslexia, cancer, menopause, chronic illnesses, neurodiversions such as autism, ADHD, age-related impairments such as hearing loss, mental health difficulties and physical disabilities.

Conferences

Promotion frameworks often require evidence for international impact, networking with colleagues on an international level and/or conference attendance. However, many disabled, chronically ill and neurodiverse staff find conferences inaccessible (see Brown et al. 2018). Issues such as travel, fatigue and the accessibility of rooms and buildings can inhibit attendance, and remote attendance is often either discouraged, or looked on negatively as a sign of lack of commitment. In-house conferences do not always factor in accessibility considerations with a centralised checklist that each symposium or event should adhere to.

Promotions

Lack of access to support and fewer conference attendances, in addition to the extra time, effort and money required to manage a chronic condition, means staff often feel that they cannot achieve promotions or maintain
a career in academia. They are either not applying for promotion, or not achieving it at the same rate as their peers. This is evidenced by the higher proportion of disabled staff nationally on zero-hours contracts or in part-time work, and the much smaller number of those in leadership roles who disclose a disability, neurodiversity or chronic illness.

Cultural and attitudinal concerns

Staff with disabilities or chronic illnesses report being stigmatised, challenged and questioned quite overtly, with some saying that they have been told they should not be trying to pursue a career in academia as they would fail anyway. Such an environment is not conducive to work, and impacts students’ experiences. If staff are encouraged not to disclose, students do not have relevant role models. An institution therefore loses potentially high-quality staff and students.

Remedial work

The common approach of remediially responding to an individual’s needs is not the most cost- or time-effective use of resources. In many cases the adjustments made would improve the experience of others. Ideally, universal design would be built in. A simple example is changing logos, branding and PowerPoint slides so that writing is not in a serif font in black lettering on white backgrounds. This benefits those who are dyslexic, have sensory processing issues and/or Irlen syndrome, and does not adversely affect the majority of the staff and student population – in fact, many report they find it easier to read. Such universal design can be applied to many aspects of both staff and students’ experiences to support learning, teaching and conferences.

Moving forward in higher education

The changes required are not quick fixes or developments that will be implemented overnight, as ultimately the entire change of an ingrained and embedded culture of ableism is required. However, in addition to those simple changes mentioned above, there are some more steps individuals and institutions can take to move things forward.
Strategy and policy

A clear strategy with a five-to-ten-year plan and the outline of a vision for what an accessible, inclusive and diverse university looks like provides the overarching framework. This is essential for charter marks such as the Athena SWAN but also for other institutional and national initiatives and frameworks. Such a clear, detailed equality, diversity and inclusion strategy needs to be set in motion with a policy signed off from the highest levels. The policy should entail quantifiable commitments such as ‘all new buildings will meet the needs of 90 per cent of all staff and students’ or ‘all events need to make use of the centrally available resources’. The policy could be linked to separate policies for specific conditions such as menopause (as first implemented at Leicester University; see Leicester University 2018), or be more general, given that many adjustments for specific conditions would also improve working life for others. Ideally, the implementation needs to be backed by high-quality institutional research and therefore seen as valuable by academics and professional services alike. Strategies and policies used in this way allow best practice to be showcased and disseminated across the sector.

Equality, diversity and inclusion ambassador or envoy

The role of an ambassador or envoy is to enforce the strategy and policies. All departments and professional services would be accountable and report to governance structures where needed. For example, if the policy says that all events need to be accessible, then the ambassador needs to have the right to check up on that, and follow through with sanctions. No policy or vision will be followed through or maintained in the long term if there is no enforcement.

Financial commitment

The implementation of the role of the ambassador and changes required (e.g. funds to support travel to conferences and the provision of support assistants for access-to-work paperwork) will require financial commitment and a budget. If the structures are changed to support staff disclosures, there has to be a budget to support them.
Leading by example

The validation of new modules, the implementation of new buildings, the employment of new staff etc. should all be checked against the comprehensive equality, diversity and inclusion policy. If all areas and aspects of academic life are governed by the policy, if staff are able to disclose their conditions, students will feel they have role models and opportunities to engage in education ‘despite’ their needs.

Ultimately, the aim of a comprehensive equality, diversity and inclusion approach would be to make a university a truly inclusive, diverse and accessible place, where gender, race, ethnicity, disabilities and chronic illnesses, neurodiversity and sexual orientation are all treated with equal respect and commitment.

References


