

## ARTICLE

# Reporting from the Margins: Disabled Academics Reflections on Higher Education

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This article is rooted in the narratives of four disabled people with obvious impairments within higher education institutions (HEI). Their lived experiences highlight how the adoption of the neoliberal agenda by HEIs has ensured the continued exclusion of disabled academics. This article shares how the implementation of mainstream business structures, and the business ethos, has been experienced by disabled academics seeking equality of education and professional academic opportunities. It demonstrates the personal impacts that can occur when institutions vehemently value income over inclusion and when academic staff adhere to these standards. If the doors to academia were closed to disabled people in the past, neoliberalism has surely locked them.

**Keywords:** higher education institutions; disability; academia; disabled; neoliberalism; academic

## Introduction

This article argues that although universities have historically been designed for able-bodied academic staff (Stone, Crooks & Owen 2013), the increased adoption of neoliberalist ideals by higher education institutions (HEI) has resulted in the further exclusion of disabled students, researchers and staff (i.e., disabled academics).

Neoliberalism is rooted in the belief that financial markets should organize and regulate the provision of goods and services to grow the economy. Over the years, HEIs have become incorporated into this ethos, and now view themselves as money-making businesses. The result is that one's value as an academic can be based upon if the HEI regards them as 'earners' or 'costers'.

Students are 'earners' for HEIs because they pay tuition but often require limited investment. Non-disabled academic staff are 'earners' because they can advertise the institution at conferences and events and work extra hours, often uncompensated.

On the other hand, 'costers' require investment to remove barriers to inclusion. These often emerge as reasonable adjustments, policy changes, or other impairment-related needs. HEIs often label these an undue hardship and regularly create complicated burdensome processes to obtaining them. The result is that disabled academics are blocked from accessing supports that can significantly contribute towards their success (e.g. interpreters). This neoliberal belief, that disability is detrimental to HEIs, regularly emanates from those in powerful positions within the HEI and often emerges as negative treatment from fellow academics.

The adoption of these neoliberal attitudes by HEIs and many of their staff members leads to disabled people feeling oppression. This article's authors felt our experiences with HEIs met Dali's definition of oppression which states: 'Oppression is both a process of bringing about the situation and an outcome of the situation whereby individual people and groups are prevented from expressing their needs, thoughts, and feelings and realizing their full potential' (Dali 2018: 491).

However, these weren't the only similarities we discovered. We found that our experiences as disabled academics converged upon numerous other topics too.

## Our shared experiences

Through our discussions, we recognised that modern-day HEIs continuously marginalise and exclude disabled people in the same manner seen in mainstream society and private industry (Kitchin 1998). We each endured this in various ways, including in our pursuits of reasonable adjustments and other provisions that would allow us to work to our fullest potential. From these experiences, we recognised that as a societal structure, HEIs do not prohibit, but rather maintain

the devaluation of disabled people to second-class citizens (Wolfensberger 1998). We also identified that part of this was due to HEIs' embracement of the neoliberal ethos, which resulted in HEIs' using power to exclude disabled people and perpetuate discriminatory norms against them, instead of using it to include them (Acheson 2011).

We felt this is seen in how, like private industry, academia applies standardised methods and approaches to labour that exclude disabled academics. These approaches construct expectations of performance based on the healthy able-bodied norm standardised throughout society (Wendell 1996). We each expressed that it is HEIs' dedication to these expectations, which contains the belief that these standards should be achievable, with no investment from the HEI, that block our full participation and inclusion into academia. When we violate these inaccurate assumptions our impairments became synonymous with inability (Stone, Crooks & Owen 2013). Our personal narratives about our experiences in academia demonstrate how these expectations and misunderstandings about disability, supported by a non-disabled academic hegemony, harm disabled academics.

Please note: Many of these narratives do not contain all the shadow barriers we face. Jason Olsen describes shadow barriers as:

Barriers that 'shadow' disabled people's daily lived experiences. These are often invisible to non-disabled people but are ever-present in disabled people's lives. Examples of shadow barriers include: unreliable personal assistance; unpredictable accessible transportation; leaking bodily fluids; and/or any other necessities tied to our impairments that interfere with our inclusion and participation. Employers and others are often unaware of or do not recognise these barriers, despite them greatly impacting disabled people's abilities to meet established policies and social norms.

For us, shadow barriers are a vital issue. We often have to contest HEIs' standardised umbrella policies before fighting the HEIs' neo-liberalistic policies concerning adjustments and other 'extra' needs. These standard policies are often designed by non-disabled staff, forcing us to explain what our shadow barriers are and that our disabilities do not begin and end upon our entrance to, or exit from, the grounds of the HEI; an issue HEIs often consider outside their scope of concern.

Historical trajectories illustrate the 'dividing practices' of segregating disabled and non-disabled learners (Borsary 1986). Our history is littered with examples of institutionalisation, segregated environments, and a continual reluctance to support our access and retention within higher education. To comprehend the extent of the barriers encountered by disabled people, it must be acknowledged that those working within HEIs have often been unaware of the role they've played in perpetuating this division. The notion of shadow barriers provides an important insight into understanding the practices disabled people previously experienced in accessing higher education, and how they affect them in the present.

Shadow barriers add another, deeper level to the requirements for this consciousness and provide insight into the variance of understanding, acknowledging and addressing the barriers disabled people face in accessing and remaining in higher education both inside and outside of the HEI. They require assessing how disabled people have been denied access and participation over extensive lengths of time and been affected by the diverse factors within political, social, economic, cultural and historical structures that produce the social world. Shadow barriers complement the social model perspective by describing disability as the unnecessary isolation and exclusion from society (Union of the Physically Impaired against Segregation, 1976), and recognise the argument of Disabled People's International (Driedger, 1989) that disability refers to the lost or limited opportunities to participate in our chosen communities and environments. Thus, visible or shadow, barriers encountered by disabled people are not caused by, nor are they the sole responsibility of, the disabled individual to address. They remain part of ingrained structures that produce our social world, and favour the ideas, strategies and activities of those who influence the organisation of HEIs.

It is naïve to suggest that individuals, committed to addressing disabled people's experiences of marginalisation, are aware of the totality of barriers encountered by individuals when navigating a disabling HEI. Shadow barriers require continual assessment and action surrounding the marginalising and discriminatory practices inherent within HEIs, particularly as HEIs respond to the political, economic and social events that affect its organisation and operations.

While we admit that some of our impairments do impose some restrictions, our lived experience tells us that it is academia's hostile cultural, social and environmental barriers that turn many of them into disabilities (Oliver and Barnes, 2010). We hope our personal experiences provide insight into the impact an increased dedication to neoliberalism has had upon our lives. We also hope that if readers recognise they've supported these regimes, they will cease to be an oppressor and become an ally instead.

### Jason Olsen

Oliver (1996) states that those who possess the lived experience of disability, and who emerge from the disability movement into academia, are organic intellectuals (Oliver 1996). It was not until I began life in academia that I recognised the shocking absence of these individuals and the damages this can cause. Let me begin by recounting something I experienced at a disability studies conference in 2018.

Upon arrival, the recommended 'accessible' hotel had a large step and no ramp. The next location provided had two heavy gates, an inaccessible roll-in shower and a bed barely off the floor—substantial barriers for a full-time wheelchair user paralysed from the chest down. The conference featured an impromptu two-mile walk to a secondary location,

in the sun, along uneven streets, with bad curb cuts. This was a tough trek for someone in a manual wheelchair, who cannot regulate their body temperature, and who was nursing a sprained shoulder.

The disability 'experts' who designed the event adopted a standardized conference structure based on non-disabled participants. Breaks were short, leaving little time for disabled people to use the restroom. Cocktail parties were in the evenings, when many people with impairments were out of energy or caring for their impairments. And networking opportunities were in places where disabled people could not move around, network or meet new colleagues. This culminated into a large discord between the inclusionary rhetoric of the conference's purpose and the ableist exclusionary practices perpetrated against disabled people attending it. This happens too often. While non-disabled academics can fully participate in all aspects of these conferences, which benefits their careers and advancement opportunities, disabled academics cannot. Sadly, this is due less to our limitations and more to HEIs that subscribe to the idea that these barriers are personal problems that disabled people must overcome if they wish to fully participate (Wendell 1996). This indifference to inclusion exemplifies how even within informed spaces, the tyrannies of normalcy and ableism insidiously dominate the academic landscape (Hodge 2014). In my case, this not only led to missed social interactions, it also led to physical injuries and a desire never to repeat this experience. This is one way academia excludes.

Another way it does so is through the targeted exclusion of one's knowledge. I also remember the visit to an independent living facility (ILF) in 2018. The leader of the educational event gathered participants together to discuss the experience. Here we were asked to give our opinions. I shared that the location gave me a visceral reaction, and I couldn't wait to leave. I stated that despite knowing it was irrational, I feared abandonment in the place we had visited. The head academic and disability 'expert' merely dismissed my feelings and comments, stating that I simply did not understand the important role these centres play, that I didn't separate my personal feelings from what I saw as a good academic should, and that ILFs are necessities for disabled people's families. She went on to state that she had recently put her mother into an ILF due to her severe dementia.

This highlights the epistemic violence (Procknow, Rocco & Munn 2017) that disabled academics experience. We often face vehement rejections of our lived experiences and are encouraged not to share our known realities. This can happen in our written works and within our HEIs. We are often told our perceptions are incorrect or 'all in our head'. However, when discussing these issues with other disabled academics, we often find that we have a shared lived experience of exclusion and a collective phenomenology of inequality. If epistemic freedom relies on the unrestricted circulation of ideas, then epistemic injustice is the denial of freedom itself (Hinchliffe 2018).

What is worse is that we are often told that advocating against this treatment can harm our academic prospects and professional opportunities. Contributing to this, HEIs often employ disability 'experts' who usually do not possess the lived experience of disability. We see these 'expert' opinions taken while our voices are silenced. Our needs go unaddressed, and any fiscal responsibility to provide us with equality is removed from the HEI. This censoring prevents the progression of knowledge about disability, and also harms the ideas creator and sharer. I know that for me, the lead academic's repudiation of my reality felt like she had reached across the table and smacked me. I had contemplated whether I should share this deeply held fear, but decided to do so for the group to understand how some disabled people do not see ILFs as viable options but as dumping grounds for the unwanted. Some of us see these facilities as warehouses to store us until our physical death catches up with our social death (Miller & Gwynne 1972).

Having this testimony met with disbelief, and its value depreciated, resulted in my feeling undermined as a knower and researcher (Hinchliffe 2018). The bases of one's academic capabilities are intertwined with their knowledge and competence, both of which my colleagues were told were negatively impacted by my disability. This is one of the issues with ableism in academia; it may be invisible to the perpetrator, but it is extremely painful to the victim (Procknow, Rocco & Munn 2017).

When contemplating what occurred, I realized that an 'expert' in the field of disability who does not value the lived experience of disability or the voices of disabled people is dangerous. As Foucault would say, she dismissed a person whose knowledge and critique could aid in evaluating 'what types of assumptions, of familiar notions, of established, unexamined ways of thinking the accepted practices are based' (Bazzul & Carter 2017). Thus, she was supporting, justifying and encouraging practices that legitimize placing a disabled person, who needs limited daily assistance to participate in society, into the same category as someone with severe dementia who requires constant assistance and care.

These reflections sent chills down my broken spine. I realized that in her position, she has the power to decide what kinds of research will be undertaken at her university and what kinds of studies her students will pursue. The research produced will justify social policies that will be put in place and impact the disability community. This is a lot of power for someone who gives little value to the knowledge, perceptions and feelings of those of us actually living with a disability.

In just one brief exchange, she'd dismissed social power imbalances that I and others face that can lead to: a loss of independent living; a loss of life choices; fears of de-kinning; inaccessible housing; ineffective pan-disability approaches; a removal of social rights; limited social inclusion; medical care barriers; medical ableism; lack of access to legislative protections; and other topics that lead to a disabled person's abandonment at an ILF against their will—something I have witnessed numerous times. Nevertheless, in her position, her university will look to her for expertise regarding disabled academics. If her view on ILFs is anything to go by, the HEI will be happy to find it has a compatriot in the belief that minimum assistance for inclusion is all that is warranted, and that if this does not address the situation, then removal from the social structure is a viable option.

I still wonder how this interaction would have progressed if the events leader had been an organic intellectual or an informed ally. Maybe they would have been less likely to discount the collective experiences of disabled people's oppression. Maybe my opinion would have been valued because they would have recognised that intellectual work is rooted in personal and collective experiences, of which I had plenty. Lastly, maybe I would not fear that this person would sell out to the highest bidder (i.e. the HEI) when it came time to stand up for disabled academics rights against the HEI's efforts to remove them from academia and thus decrease their costs (Oliver 1996).

### **Armineh Soorenian**

#### ***Silencing disabled academics' voices***

Through ableist norms, disabled staff and students' voices have been disavowed and suppressed under the violence of the neoliberal system pervading today's academic institutions (Campbell 2018). Evidenced in the suppression of my own experience throughout my academic journey as a student first, and, since 2012, as an academic, this situation has perpetuated the legitimisation of the complex webs of structural inequalities present in HEIs. I have experienced multiple discriminations grounded in being 'disabled', 'international' and 'woman'. In my contribution to this article, I will write how in the ableist academia—enshrined within the maintenance of the dominant ideology—attitudinal barriers and discriminatory practices have worked hand in hand towards my exclusion and marginalisation. I will then explain the damaging effects of such practices on my self-esteem and confidence.

#### ***Attitudinal barriers***

To demonstrate a political, economic, social and cultural privileged position, it's expected that academics master a specific form of articulation when communicating, such as expressing their views or putting forward an argument. This ableist norm of elegance has worked to differentiate, divide, rank and colonise academics. Following a brain injury almost three decades ago, I have dysarthria, which is speech that is difficult or has unclear articulation. While outside academia, people usually respond to my slow and slurred speech in patronising or impatient ways, or both, in academia this type of overt verbal treatment is generally absent. However, the underlying biases and prejudices remain deeply ingrained in some academics' attitudes, whereby I'm not taken seriously or seen as an academic in my own right. These preconceived notions are held without recognising that I've managed research projects and produced a large quantity of high-quality written work in English, which is my third language, for over a decade. Consequently, I'm either not given adequate time or space to express my views, as this would fall outside the able body norm and may require a slight increase in costs. My arguments are often discredited and dismissed outright without a willingness to be understood. This too appears to be what fellow academics would consider a 'waste of time'.

#### ***Discriminatory practices***

With a focus on standards, league tables and achievements, the need for extra time and extensions isn't desirable or even recognised as possible in the neoliberal academic environment. High productivity is expected in compressed time frames, and increasing demands are placed on academics' time with teaching workloads and pressures to publish over the life of their fixed, short-term contracts. One of the side effects of my medical condition is that I need more time to process information, reflect and prepare my responses, a situation not necessarily conducive to a traditional academic culture or typical interview situations. Everyday tasks take longer; I may require double or even triple the time of that taken by a non-disabled researcher to complete the same work. I also have a visual impairment, and converting standard print written materials to a format that I can access is a very time-consuming process. Wendell (1996: 30) refers to such impeding effects on time and energy levels, when disabled people make accommodations to their physical environments to overcome access barriers, as 'ordinary living arrangements'. However, in a working environment, where overwork is normalised (Brown & Leigh 2018), I've truly performed like a 'super cripple' (Oliver & Barnes 1997) by working over and beyond the hours expected of an academic, even in full-time employment. I've held onto my academic work and identity whilst compromising my physical and mental health and other aspects of my life. Additionally, some days I experience extreme fatigue, which, together with chronic migraines that occur regularly, could delay the completion of work by days if not weeks. Sadly, in academia, little accommodation is made for disabled academics who may need extra time for impairment-related reasons. Thus, as Kumari-Campbell (2018) argues, ableism in favour of non-disabled people is endemic in academia.

Long-term academic mobility is a significant career improvement tool, yet this is often a barrier in disabled people's lives. Moving universities is often stressful at the best of times. Disabled people must also contend with the complications of finding what support is provided in the new place of residence and if it meets their disability-related needs and requirements. This situation exaggerates the demands placed on disabled academics compared with non-disabled scholars, since often academic mobility opportunities are designed around non-disabled masculine practices, without considering the existence of disability and impairment-related access needs or family care responsibilities (Shauman & Xie 1996). As the capacity of the welfare state and other benefits result in fading support structures and transparent career paths in a neoliberal context (Caretta & Webster 2016), these conflicts are exacerbated and felt more acutely by the disabled academic community. Academia thereby poses disabling contexts for academics, and ableist social relations privilege and entitle non-disabled academic bodies.

### ***The psychological impact***

The numerous barriers I've experienced in my academic journey have been multi-layered and multifaceted. The way my speech impairments have been dealt with has made me reluctant to contribute in academic and social settings, as it has left me feeling that I would not be understood, so why try? The feeling of isolation—not belonging, and not fitting in both academically and socially—has been damaging and destructive to my self-esteem, resulting in years of trying to constantly prove myself, yet feeling inadequate and uncertain in the academic sphere and in other areas, despite clear proven successes. I've blamed myself for my disadvantages rather than affirming that these beliefs are constructed within me by socio-economic political oppressive systems. Freire (1970) argues that this dominant ideology is mostly invisible to the oppressed group because their perceptions of themselves are submerged in the reality of oppression. The layers of oppression I have accumulated inside myself have become internalised, mostly resulting in permanent panic, depression and competition with others.

### ***We are valuable***

As a disabled woman with multiple impairments, an academic with a different linguistic and cultural background, and as a disability activist, I've been subjected to the microaggressions of the neoliberal academic system. These have taken forms of subtle humiliation and sometimes non-verbal exchanges and reactions, which according to Kumari-Campbell (2018) decreases the character or quality of a person by lowering self-esteem, leading to anxiety, social phobia and depression. Through the use of ableist tactics, the academic relational dynamics make disabled students and staff's experiences invisible at best, or at worst erase them, fostering conditions of microaggressions and internalised ableism (Kumari-Campbell 2018). The side-lining of the disabled academic community's experiences has led to their exclusion and marginalisation, which has resulted in wastage of disabled people's voices, accounts and skills. To bring about change, so that disabled academics' voices can be heard loudly and clearly, this ought to be thoroughly challenged by the academic and disabled activist community at large. We're disabled academics, and though some may feel we're disturbing the normative ableist structure of academia, we're here to stay and showcase our experiences, skills, projects and other academic output just like our non-disabled peers. While some may consider our inclusion in HEIs in monetary terms, such as providing facilities and support, our presence and participation in HEIs must not be perceived in these terms. If HEIs place value on our lived experience of disability, the flexible and out of the box thinking that we have developed because of the daily barriers we face in our lives, to name but just two, then this perspective adds to our academic value. Once our support needs are met, we are enabled to make meaningful and impactful contributions not only for our HEIs but for society at large.

### **Miro Griffiths**

The realm of academia continues to be a contested area for activists, scholars and policymakers. It should exist as a platform to explore, challenge, critique and put into practice historical and contemporary models and theories. Instead, HEIs are plagued by neoliberal agendas that prioritise: the economic viability of educational institutions (Hazelkorn 2015); the competitiveness between learners to attain the highest grades (Verhaeghe 2014); and the implementation of an educational model that emphasises conformity over creative inquiry (Chomsky 2012). With academia in crisis, there is an opportunity to consider how disabled people navigate this complex, inaccessible and ableist structure. As attempts are made to establish methods which counter the neoliberal condition within HEIs (Cannella & Koro-Ljungberg 2017), there is a desperate need to use this period of crisis to identify problems and advance solutions to address the micro-and macro barriers encountered by disabled people. As a contribution, I will draw on personal experience to highlight three aspects that require attention if there is to be an accessible and inclusive higher education system. Firstly, I'll discuss how the current assessment procedures to identify 'health', 'social' and 'academic' needs restrict participation and further marginalise disabled people from higher education. Secondly, I will discuss the absence of disabled people and their organisations within the design, development and delivery of assessment procedures to identify and address disabled learners' access requirements. I'll conclude by speaking about the apathetic response from HEIs to address the political issues and concerns raised by disabled activists and their organisations that negatively impact disabled academics.

### ***'We provide geriatric care; we will not support you when you are at University. Good luck.'* – Assessment procedures**

Prior to starting University, I was in receipt of joint 'health' and 'social care' support. My 'academic' support needs had been assessed, but the professionals associated with my care plan had not discussed how the support would be delivered throughout the academic calendar. There were disagreements: 'academic' support wouldn't include 'personal care'—I could study, but the assigned support worker wouldn't assist me to use the toilet or consume any food/drink; 'social care' would be provided, but it was too costly to have a personal assistant stay for the entire day. The disagreements continued, and two days before my first lecture I received a phone call from a private care agency. They had been assigned to support my 'personal care' needs; however, as quoted above, I was informed I did not meet the criteria to receive support. For the initial few months, I relied on volunteers to help me eat and toilet. When I required more structure, I obtained a student loan, not for extra educational opportunities, but to pay for assistance. Eventually, a somewhat workable solution was implemented, but I was exhausted and outraged.

The literature illustrates the extensive barriers encountered by disabled learners as they navigate higher education (Kendall 2016), and my experiences validated them as true. Discussions concerning assessment procedures typically focus on the ability of the learner to perform tasks and examinations within the established curriculum (Fuller, Bradley & Healey 2004), with little attention towards ensuring an individual receives the right level of support at the required time.

The Independent Living Movement (Evans 2008) demands that support is provided to enhance an individual's autonomy and realise their aspirations. However, there's substantial risk that experiences such as mine—and others (Pring 2015)—will continue due to fragmented, underfunded services that offer reactionary responses to individuals who require support. Detrimental cuts to local authority services, (O'Hara 2014) combined with social care policies framed to dismiss the needs of working-age people, will lead to HEIs becoming an unrealistic ambition for disabled people. I was made to feel I was an inconvenience to the rigid assessment procedures, which refused to account for the fluctuating and spontaneous experiences I would have at University. Professionals, who were preoccupied with meeting budgetary constraints and implementing policy procedures, abandoned me.

If we wish to change this, we must resist current practices and propose alternative options to identify and provide support to disabled people. As Morris (2011: 1) suggests:

disability policy [...] must value diversity and in which disabled people are treated as belonging and contributing to the communities in which they live. [...] We need to develop more radical challenges to the current disability policy agenda and engage in wider debates.

To continue this line of thought, I will focus on the specific experience of 'academic' support.

***'Just stop. I'll advise you later on what you can have. Most importantly, when was your diagnosis?' – Design, development and delivery of assessment procedures***

When I got to University, I attended an assessment for Disabled Student Allowance. While trying to explain I had researched which assistive technology devices would help me during my studies, and that I had created a support plan outlining when (and for what purpose) I would need a support worker (and could justify this due to my access requirements), I was told to stop talking. Even though I could reference the '12 Pillars of Independent Living' and had a basic grasp of *Pride Against Prejudice* (Morris 1991), I felt a disconnect between the hope articulated by prominent scholars and activists within Disability Studies and my lived experience of oppressive structures and attitudes. The assessor wanted to focus on impairment diagnosis and presented a catalogue of questions rooted in medical discourse. It became uncomfortable to discuss my access requirements with someone who fixated on my body instead of the barriers emerging from my programme of study. Furthermore, the professional status of the assessor, and the authority he commanded, reduced me to feeling inferior, broken and in need of repair through his advice—I was experiencing ableism (Kumari-Campbell 2009) from the person designated to assist me in overcoming it.

Scholars have discussed the barriers encountered by disabled students as they access support, raising concerns about: institutional culture towards inclusive learning environments (Fuller, Bradley & Healey 2004), disclosure (Goode 2007) and implementation of reasonable adjustments (Hewett et al. 2018). Such discussions are required but are limited in their application; instead, a radical overhaul of the assessment procedure is needed. The absence of disabled people and Disabled People's Organisations to design, develop and deliver assessments of support must be evaluated and acted upon. The Disabled People's Movement will continue resisting cuts to Disabled Student Allowances (Lewthwaite 2014), but disabled activists, their allies and HEIs must offer an alternative vision for assessing and providing support. This means universities must respond to the political concerns raised by disabled people.

***'Your feedback is really important to us.' – Political concerns, apathetic responses***

Vickerman and Blundell (2010) reported on disabled people's lived experiences of entering university and, ultimately, seeking employment. The study highlighted areas of investigation, which included: pre-enrolment and transition to university, teaching and learning, and career development. Whilst important, such literature does not go far enough to question how HEIs acknowledge and respond to the political issues raised by disabled student activists and their organisations. All too often, I was invited to attend 'student pizza parties' (paid for by the university) or offered discounted tickets to dance nights (subsidised by the university). This was provided at the same time as I navigated inaccessible environments for a wheelchair user and met disabled students who had to leave their studies because their support packages collapsed. I continue to be outraged by the decision-making processes that fund opportunities for students to engage in consuming extra resources while disabled students are being denied basic access to education. Bauman (2007) discussed how economies orientated towards consumption will, inevitably, promote dissatisfaction and insecurity. This is the contemporary experience of disabled (and non-disabled) students in higher education. Universities fail to address questions, such as: What's the point of education? What's meant by inclusion? How do HEIs contribute towards the marginalisation of learners and scholars? Yet, institutions appear reluctant to proactively address these questions and the demands and concerns raised by disabled students.

The issues I have raised—assessment procedures, involvement of disabled people, and institutional responses—require serious attention if an inclusive higher education system is to be realised. The political and economic crisis afflicting

HEIs will continue, but this provides an opportunity to realise alternative possibilities for the inclusion of disabled people within academia.

## **Rebecca Porter**

### ***Introduction***

Society often views the disabled person as a lesser person. It permeates every part of life, including that of the academic. I have spent four years in university. In that time, as a disabled woman, I have faced unsurmountable pressure to perform at the same level as my peers. But in truth I can't, and the toxically high production standards academic culture prides itself on are unattainable to someone like me. While my impairments can deeply affect my academic performance, to varying degrees the impact of them can be lessened with appropriate reasonable adjustments and expectations. However, this can only occur if the HEI is willing to provide them.

My first experience of ableism came long before my discovery of the social model of disability. It was 2014, approximately my third or fourth week of my first semester. As the first in my immediate family to attend university, it was like walking into an exciting, rather terrifying black hole. I had recently received monies from the Disabled Student's Allowance (DSA), which funded software on my laptop to help me take notes. My lecturer walked into the room and refused to start the lecture until everyone put their laptops and notebooks away, only allowing students to annotate the handouts he had provided. He said we would learn a lot more by listening. I sat there for an hour and learnt nothing. This policy was applied to not just the lecture but to the modules seminar group the following day: no one could discuss the lecture, and we stared in stunned silence at my seminar leader.

I sought help from study support, but there is only so much an hour of 1:1 learning support can do for a stressed disabled student with a high workload and no notes. I relied heavily on my friends to support me because the academy had failed to do so. My mental health suffered severely, but if I was achieving my grades, it felt as though very few people cared. As my chronic pain and fatigue worsened with each year, and I was having long depressive episodes and spells of heightened anxiety, my allocated funding for hours of 1:1 support dwindled. I had fewer hours to discuss my essays and almost crumbled under the pressures to attain high grades. It was clear to me that my costs to access the HEI clearly outweighed my perceived value. Increasingly, I find the pressure never emerges from lecturers directly (I am very lucky in that sense that disability studies lecturers 'get' disability). It comes from toxic work cultures in academia that stem from neoliberal ideas of production, the goals of which are often untenable by disabled academics, especially by those who are unsupported.

### ***Accessibility and academic tradition***

As I progress through academia, dealing with my own internalised ableism has been one of my toughest challenges. There are lots of pressures and demands to keep up with deadlines. Thrown in, however, is the idea that in their spare time students and staff should also be attending conferences, volunteering, maintaining a family life, and having a social life. Under the weight of these obligations, can we really be surprised that many academics are experiencing a mental health crisis? (Universitiesuk.ac.uk 2018) I know for me at least, the toxic university culture results in feeling guilty for being unable to reach prescribed, yet unrealistic, ableist expectations (Brown and Leigh 2018).

### ***Does academia work for anyone?***

My outright answer is no. No matter who you are, your background, your expertise, I feel all academics struggle under the weight of university culture. Under this hegemony, you can't work too hard, you can't put too many hours in, both paid and unpaid, and exhaustion is almost a requirement. I fear this culture heavily affects all academics, regardless of position- from first-year students to the highest of senior lecturers, but it disparately impacts disabled people. This results in disabled people's leaving academia; universities with disability studies curriculums, and more broadly, those with social science departments, lose disabled people's lived experiences and expertise.

### ***Disability, the academy and beyond***

Activism, in any form, is a way forward for social change. But this can only occur if there are enough people to speak out. Without them, disabled people will remain the scapegoats of bad policy. Academia plays a key role in this potential liberation because if society will not listen to those who are oppressed, it's up to those with the power and resources for social change to do good. Education, and the highly inaccessible world of the neo-liberal academy, is a potential space for this (Goodley 2014). But it must be done in the right way. During my time at University, I have been supported by fellow students and lecturers alike and made to feel I'm understood as a disabled student and researcher. However, I still feel at times that the emotional and physical labour academia carries is untenable. In the past, trying to keep up with everything has led me to feel like I was drowning in obligation. I have learnt the hard way that my health comes first, that letting things go for a few days doesn't equate to failure, and that my exhaustion is valid.

In this messiest of debates, I know one thing is clear: disabled people need ownership of our identity. Disability isn't something to be 'dealt with' by universities, but something to be accepted and included. I have lost count of how many student union election posters I see, who talk about diversity but do not present disability as another intersection where people can experience oppression. Disability is the biggest intersection we have, and it requires more acknowledgement

than just being an hour a week where you're helped with work. In the classroom, in the street, wherever I go, I do not just want acceptance and toleration; I want full inclusion and liberation.

## Conclusion

Historically, higher education made little attempt to include disabled people as learners and scholars. Where opportunities—albeit limited—arose to build an integrative higher education system, or aspire towards incorporating inclusive education principles, few tried to do so. Those that did have been dismantled or eviscerated due to the entrenchment of neoliberal ideals. This has resulted in poor retention levels of disabled people in higher education and worrying signs of growing attrition within HEI (Brabazon 2015) staff. The exploration of the lived experiences in this article illustrates that disabled people are attempting to navigate a system designed by, and for, non-disabled people. The authors identified how aspects of the neoliberal agenda have perpetuated the barriers imposed upon disabled academics. This marginalisation demonstrates that, due to the adoption of neoliberalism as an ethos, the passage of time has not resulted in positive systemic changes in HEIs for disabled academics. We've argued that the doors of academia are shut for many within the disabled people's community, although—as our testimonies show—some of us managed to slip through the keyhole.

Instead of advocating for disability inclusion, most HEIs have instituted policies, procedures and attitudes designed to cultivate colonisation and stigmatisation (Reutlinger, 2015). These efforts are rooted in a neoliberal dedication to fiscal conservatism that harms disabled academics by removing our access to equity.

This has contributed to disabled academics being framed as 'costers.' As 'costers' we are perceived to 'cost' the HEI money for daring not to have the physical stamina to work extra hours, often gratis, to the HEIs benefit. We often face resentment from the HEI, due to its being asked to spend monies on adjustments, when they question if the investment in disabled academics is worth the productivity that will result from it (Hazer & Bedell 2000). The consequence is that we often cannot fully demonstrate our knowledge and capabilities. This in turn blocks us from inclusion and advancement, relegating us to the margins of academia. As part of an accepted structure, these approaches often block our non-disabled colleagues from recognising the social injustices we face. Instead they are led to believe our lack of advancement is a natural and inevitable delineation between the capable and the incapable (Cundiff & Vescio 2016). The result is that fellow academics see us as objects of pity and as institutional burdens who do not possess the competence necessary to perform in the academic sector (Wolfensberger 1998). While many of us are acutely aware it's our responsibility to manage the stigmas against us if we wish to minimize the prejudice and biases we will face (Gioaba & Krings 2017), this discrimination can be hard to endure on a daily basis—even more so when it is experienced not just from leadership, but from co-workers and others who believe incorrect narratives about our worth and our ability to contribute.

These conclusions are often not challenged but are supported by the non-disabled 'disability experts' HEIs have hired. This is not an accidental occurrence, as HEIs create power-relationships that deny disabled people access to important decision-making positions that could repudiate its exclusionary practices (Kitchin 1998). Unfortunately, the lack of disability voices in academia has meant that current truth regimes in institutional arrangements have gone unchallenged on an international level within academia (Bazzul & Carter 2017). Until disabled academics are in real places of power, this negativism will inexorably lead to their further exclusion. We've already seen this in the low representation of disabled academics employed by academia (Brown & Leigh 2018).

Accomplishing this has many obstacles. The largest is that this would require disabled academics' acquiring positions of influence within institutions where their expertise is not sought nor welcomed. What makes finding individuals for these positions even harder is that the neoliberal ethos has discouraged staff who possess expertise, derived from the lived experience of disability (i.e. organic intellectuals) (Oliver 1996), from remaining in academia in face of such large oppressive forces, let alone fighting for a position of power they are unlikely to obtain.

Make no mistake, this exclusion is a consequence of deliberate actions by policymakers and those who have considerable influence (Griffiths 2017); therefore, disabled people and their organisations must continue to mobilise, strategise, and advocate for the specific changes required to realise a safe, fair, and inclusive society. A part of this means ensuring that administrators begin to consistently consider disabilities and chronic illness when they create policies to ensure employee wellbeing (Stone, Crooks & Owen 2013). This must include policies that are sensitive to shadow barriers and whose core does not subscribe to the belief that disability is a fiscal detriment to the HEI warranting a person's removal.

Our call for solidarity and change is not directed only towards HEI leadership, disabled people, and their organizations. We call upon non-disabled students, researchers, co-workers, and scholars to decide which side they are on. As Becker (1967) argues, people must decide whether they are on the side of the oppressed or the side of the oppressors—there is no middle ground. There is a desperate need for non-disabled allies to support our campaigns and demands for institutional change. We hope our stories are used to build solidarity with those who continuously resist the ableist agendas plaguing academia and that they are used to explore HEI structures and create alternatives to how they're organised. Until this happens, the doors to academia remain closed to the disability community. Some of us have managed to slip through, but remaining inside is a constant struggle.



## Competing Interests

The authors have no competing interests to declare.

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