Abstract

This article offers a contribution to understanding how both disablism (the direct experiences of exclusion and discrimination faced by disabled people) and ableism (the norms and codes that shape our understanding of dis/ability) can manifest in the lives of students attending Higher Education. This is based in my research with people living with chronic illnesses in England and Portugal. I argue that being attentive to the conditions that produce barriers and exclusion for people living with chronic illnesses attending Higher Education continues to be imperative in order to tackle such barriers, particularly in contexts like Portugal, where such barriers remain prominent. In addition, understanding and unravelling the norms and codes that affect our understanding of normalcy and disability is equally fundamental in order to continue to enable true equality for disabled people.

Keywords: disablism; ableism; chronic illness; Higher Education;

1. Introduction

This article discusses issues of access and reasonable adjustments that can be encountered by people living with chronic illnesses attending Higher Education. The article draws from two narrative accounts received as part of a larger study about the lives of people living with chronic illnesses and uses these as case studies to discuss some of the issues that can shape the educational experiences of people living with long term conditions in Higher Education. The article is framed by a disability studies framework and draws from theories in the field to illuminate some of the issues reported by participants in this study. I argue that a disability studies perspective is important when it comes to understanding the accounts of people who live with chronic illnesses for several reasons. Firstly, chronic illnesses can be seen as a category of impairment ([Thomas, 2007](#_ENREF_43)). Secondly, because people who live with chronic illnesses face exclusion and discrimination as I have documented elsewhere (author, date). Therefore, trying to understand how institutions respond to the needs and reasonable adjustments required by people with chronic illnesses is important. People who live with the illnesses this study focused on, namely fibromyalgia, chronic fatigue syndrome, myalgic encephalomyelitis and multiple sclerosis, do not always have visible signs of impairment (although they can) and, when this is the case, they can often be perceived by others as being non-disabled. Thus, they can inhabit a kind of in-between space where sometimes they can pass as non-disabled or be identified as such by others. This has deep implications for how others perceive them as well as for how people perceive themselves and their identity since it frequently means people must make a decision to disclose their impairment to others if they need this to be acknowledged. This also applies to students living with chronic illnesses. Participants in this study also reported a general lack of knowledge and understanding about these illnesses both from friends and family members as well as the general public. This in turn influences how people are treated or the expectations that others have from them.

This article focuses on the reported experiences of two students who attend Higher Education institutions and live with a chronic illness. One of the students attends a University in England and the other studies in Portugal. This is based in my comparative research with people living with chronic illnesses in both countries in which I solicited personal accounts that focused on any aspects participants decided to offer about their own lives. There has been a lack of research regarding people who live with chronic conditions and their presence in Higher Education from a disability studies perspective (although literature focusing on disability and Higher Education is more common) – this paper intends to contribute to this gap in knowledge. Equally, the article intends to contribute to a deeper understanding of how both ableism and disablism can manifest in the lives of some people living with chronic illnesses as well as the ways these two aspects can significantly shape their lives.

The two accounts chosen, then, intend to offer an illustration of how disablism and ableism can be present in the lives of people who live with a chronic illness, especially in the context of Higher Education. Although disablism has been extensively theorized from a social sciences point of view, especially in Britain ([Barnes, 2012](#_ENREF_3); [Thomas, 2007](#_ENREF_43)), ableism is still somewhat less explored, especially in the context of empirical data. This article however proposes to shine a light on how ableism can have a bearing on disabled people’s lives, especially in the context of education. Although there have been some important contributions to the study of ableism from a disability studies perspective, many previous studies have tended to offer a theorization of ableism without engaging with empirical data.

1. Approaching disablism and ableism

In the context of the British Social Model, disablism has been the word used to signify the barriers, exclusion and discriminatory practices experienced by disabled people. It therefore focuses on the lived experiences of disabled people and how their lives are affected by this. It is the equivalent term to racism or sexism in that it allows us to express how an oppressed population is affected in particular ways ([Barnes & Mercer, 2003](#_ENREF_4)). The term disablism was first proposed in order to offer an understanding of the social barriers experienced by disabled people and how, these, and not the impairment, shape the experience of disability. Carol Thomas then extended the original UPIAS ([1976](#_ENREF_47)) definition of disablism to include psycho-emotional manifestations and offered an expanded definition: ‘Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.’ ([Thomas, 2007:73](#_ENREF_43)). As Dan Goodley argues, this has been important ([Goodley, 2011:9](#_ENREF_16)) because it recognizes disability ‘as a phenomenon of cultural, political and socio-economic conditions’.

Ableism, on the other way, is a term that refers to the larger framework that governs our society’s understanding of ability and disability – this includes the often untold norms and codes that shape our understanding of bodyminds ([Price, 2011](#_ENREF_35)) and our notions of disability. In this regard then, it is more equivalent with terms such as patriarchy and whiteness ([Mallet & Runswick-Cole, 2014](#_ENREF_30)) as it allows us to focus on the systems of beliefs and values that underpin our understandings of ability and disability and that allow for disablism to occur in the first place. In previous work (author, date), I have defined ableism as a system of beliefs that privileges normate notions of the body/mind and ability that are culturally constructed and views disabled people as inferior and lacking. The concept focuses on how society artificially constructs notions of normalcy. Some authors in disability studies have offered significant contributions which have shed a light on the importance of understanding the role of ableism in disabled people’s lives ([Campbell, 2009](#_ENREF_6); [Goodley, 2014](#_ENREF_17); [Titchkosky, 2007](#_ENREF_44), [2011](#_ENREF_45); [Wolbring, n.d.](#_ENREF_52)). Thus, looking at ableism definitely shifts the terms of engagement from seeing disability as pathology to being attentive to the many ways normalcy is artificially produced and maintained. Even though this shift is recent in the literature and there is no clear consensus on the characteristics of ableism, Fiona Kumari Campbell mentions that ‘a chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of ‘type’) is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated.’ ([Campbell, 2009:5](#_ENREF_6)). Furthermore, ableism and its emergence from a modernist stanza, creates at its core the able versus not-able divide and presents these as two distinct and ‘clear ontological zones’ ([Campbell, 2009:6-15](#_ENREF_6)). This creates problems because, as she mentions, ‘inscribing certain bodies in terms of deficiency and essential inadequacy privileges a particular understanding of normalcy that is commensurate with the interests of dominant groups (and the assumed interests of subordinated groups’ ([Campbell, 2009:11](#_ENREF_6)). Thus, looking at ableism means looking at the beliefs and expectations our society has about bodyminds.

I argue that recognizing the importance of how both operate in disabled people’s lives is crucial to really challenge the fundamental ways in which disabled people find themselves at a disadvantage in contemporary societies.

1. Disability and Chronic Illness

Although the most common terminology in governmental and policy documents these days tends to be long-term conditions ([Long Term Conditions Team, 2012](#_ENREF_28)) instead of chronic illnesses, I prefer to use the latter in this article since it tends to be widely used by patient groups and advocates. Chronic illnesses can be described as long-term conditions that will not go away with time and cannot reliably be cured ([Wendell, 1996 20](#_ENREF_49)). Even though, many people may not perceive people living with chronic illnesses as disabled, and many of the study’s participants did not construe themselves as disabled, I argue that it is pertinent to conceptualize chronic illnesses within a disability studies framework since the research demonstrated that structural, contextual and social policy factors greatly influence people’s lives, beyond the embodied experience of the illness alone. These factors are crucial to acknowledge and understand since they can be changed whereas the physical experience of the illness often is difficult to change.

1. Methodology

This paper is based in my research with people living with chronic illnesses in England and Portugal. I chose to focus in England, as opposed to the whole of the UK, in order to concentrate only in one legislative context and compare that to the one of Portugal. I was specifically looking into Fibromyalgia (FM), Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME) and Multiple Sclerosis (MS) which are all illnesses that cause an array of difficult and debilitating symptoms such as widespread pain and fatigue. I had two main lines of inquiry. Firstly, I wanted to find out if people living with chronic illnesses experience disablism – that is, whether they experience discrimination and exclusion. Secondly, I wanted to ascertain what kinds of knowledges and strategies people living with these illnesses develop and enact in their lives through their experience of impairment. This paper will focus on themes and accounts related to the first research question.

 I wrote and distributed an invitation which included questions and topics related to what I wanted to find out in the research and asked possible participants over 16 years old who self-identified as having these conditions to write or record an audio account and submit it via a website which included a short survey as well. I gave prospective participants a number of possible topics that I was interested in and they were allowed to explore the topic as they wished. I then engaged in further conversation with some participants via email and asked them to elaborate further on particular aspects their accounts had highlighted. This allowed participants to engage with the research at their own pace and in their own time as opposed to being pressed by strict interview schedules which can be taxing. Since participants’ symptoms fluctuate a lot, it was important that they would be in control over their time and energy.

 I received a number of narratives that focused on different aspects of people’s lives, therefore, not all of them focused on Higher Education. However, the issue of disablism and ableism came up in other contexts too (such as employment) and I try to notice these connections throughout the article.

I used the narrative correspondence qualitative research method which involves soliciting and engaging closely with the written or spoken personal accounts of participants ([Grinyer, 2002](#_ENREF_22); [Milligan, 2005](#_ENREF_32); [Thomas, 1999](#_ENREF_42)) and documentary research analysis ([Duffy, 2005](#_ENREF_9); [Jupp & Norris, 1993](#_ENREF_26); [McCullock, 2004](#_ENREF_31); [O'connor, 2007](#_ENREF_34); [Prior, 2003](#_ENREF_36); [Scott, 2006](#_ENREF_39)), which involves the use of texts and documents as source materials in social research. I used this method to supplement the information received through my primary method and specifically to analyse social policy and legislation documents. I received a total of 32 accounts from both countries which were then organized thematically and analysed using narrative analysis ([Andrews, Squire, & Tamboukou, 2008](#_ENREF_1); [Squire, 2008](#_ENREF_40)).

Narrative analysis focuses on stories as narration of events which can be sequential in nature ([Grbich, 2007](#_ENREF_21)). It prioritizes the importance of stories and sees these as essential to our understanding of ourselves, each other and the world. Narrative allows us to focus on how stories are told, their structure, who produces them, how they are received by others, how they might circulate or be silenced ([Squire, Andrews, & Tamboukou, 2008](#_ENREF_41)). As Arthur Frank contends in regards to narratives about illnesses, stories allow people to make sense of their experiences ([Arthur W. Frank, 1995](#_ENREF_13); [Arthur W. Frank, 2010](#_ENREF_14)). Narratives of experience, in particular, are not the ‘real truth’, they represent a subjective account that is unique to that person. They are a re-configuration, a re-presentation of experience, however, they do point to aspects of real life that can then be corroborated by official documentation, legislation, policy documents and others ([Squire, 2008](#_ENREF_40)). They re-represent personal experience through language and therefore allow for an insight into how someone is making sense of their lives as well as significant external and structural aspects that might have had an influence in their life.

Unlike what happens with other methods, narrative approaches place a lot of importance in the context of the account and not so much on the researcher’s summary of participants’ input. With this in mind, I draw on somewhat larger extracts from participants’ accounts which I contextualize with the help of official documentation. This research has placed quite a lot of importance in highlighting participants’ accounts in their own words as one of the most recurrent issues in the research was participants’ concerns around what they perceive as a general lack of knowledge or understanding about the illnesses that the study focuses on. Therefore the ability to have participants’ words featured in detail is also a choice to allow participants to have a direct say on the matters being discussed. I include a fictional name, sex, country, age range and illness(es) at the end of each extract in order to provide the reader with a snapshot of information about the participant instead of providing a short portrait of each participant featured in this article.

1. Chronic Illness and Disablism

Understanding how disablism affects disabled people is a fundamental part of tackling oppression and fostering equality. Exclusion and oppression for disabled people in education can occur in a manner of different ways: from buildings that are inaccessible to school systems that cater for the needs of only some bodies and minds, normalizing the needs of some and pathologising those of others ([Barden, 2012](#_ENREF_2)), to the fact that the school curriculum itself does not include the history or experience of disabled students or indeed excludes disabled people from the types of representations available about other groups ([Beckett, Ellison, Barrett, & Shah, 2010](#_ENREF_5); [Hodkinson, 2012](#_ENREF_24)). The two narratives I include here, focusing on students attending higher education institutions, can shed some light into specific issues experienced by some students living with chronic illnesses – these accounts are not by all means representative of all the issues that people with these conditions might experience but they invite a particular vista into some of the issues experienced that allows us to identify bigger patterns that might be shaping some of the experiences of people who attend higher education institutions. They also allow me to point to a more general legislative and cultural framework that will frame the lives of people and whose importance cannot be denied.

One of the accounts received was a rather extensive account focusing on the situation of a student living with a chronic illness who attends a Portuguese University. This account focused on many types of barriers that the student reported facing during her course. Mariana, who had been diagnosed with chronic fatigue syndrome and fibromyalgia, reports that she attended University part-time due to some of the demands of her health condition. She had only realized that there was an office for students with special educational needs when she had already been at University for a few years and she only found this out through talking to another student who also had a chronic condition and was being supported by the same office. She mentioned that asking for support was helpful but it also had its drawbacks. She describes feeling discriminated against when Professors knew she needed reasonable adjustments as she felt some staff did not think this was merited. She also provided a detailed account of feeling singled out during an exam (which relates to how the Portuguese system works):

When I started being supported by the office for students with special educational needs sometimes it became counter-productive. Once I was [enrolled in a class] and during the written exam I was entitled to having an extra half an hour. I was in an auditorium filled with students and the professors did not know who I was. The professor asked who I was [said my name]. I was horrified because there were maybe 200 people in that room but finally I had to say it was me. I spent the rest of the exam trying to block the humiliation of having everyone looking at me but it was very hard. I felt ashamed. I didn’t think it was the Professor’s fault since the system doesn’t really work very well. Sometimes I could not go to class because I was unable to go and the professors did not know who I was. Whenever I could, I would try to explain to my professors that I had this illness and I would ask them, after this incident, to be discreet. I felt I was being discriminated against and that Professors looked at me in a strange way once I disclosed this information. (Mariana, Female, Portugal, 31-40, Fibromyalgia, Chronic Fatigue Syndrome)

On the one hand, this account speaks to the lack of information regarding disability issues that can still take place in Portugal where students may not even know what is available to support them. On the other hand, it is related to the fact that legislation that provides disabled students with what the legislator terms ‘specialized support’ in education ends in year 12, when compulsory education terminates, just before students enter University (["Decree-law n.º 3/2008," 2008](#_ENREF_8)). This has an immediate consequence on the types of support available to students such as Mariana as well as on the lack of preparation Professors may have to understand and support disabled students in her situation.

 In addition, these aspects reported by the student speak to wider issues associated with labelling disabled students in education ([Ho, 2004](#_ENREF_23)). When students are not labelled in education that often means they are not able to access any support or reasonable adjustments. Therefore, before Mariana realized she could maybe get a bit more support, she was mostly dependent on her Professors’ good will since no formal process had been put in place that meant she had the right to access reasonable adjustments. However, as soon as she became involved with the office that supports disabled students she was now part of a framework of support through the use of some of the University’s rules and regulations that were in place. But this also meant disclosing the label and, by doing so, placing herself in a situation where others would be able to make judgements of her that were now more based on the label than on their understanding of the person. Therefore, she reports that this situation made her feel more discriminated against than before. The incident she reports, where she was asked to identify herself during an exam meaning the other students would be aware that she had been classified as having special educational needs, is particularly horrifying since she might have not been willing to disclose her condition to her other classmates. Yet, she was placed in a position of forced disclosure which would be uncomfortable for anyone. Later on, she explained she felt some of her marks did not reflect the effort that she felt she had put in but were maybe influenced by the Professor’s view of her through a label. These aspects are of course very subjective as students often can feel that more effort on their part should lead to better marks but she reports a real gulf between the attitudes of Professors before she shared the label and after this occurred.

A system that does not account for the access needs of disabled students is clearly imposing particular kinds of barriers that will disadvantage students in particular ways. Having to fight for recognition of a person’s access needs and having to deal with justifying those needs in the first place, constitutes an affront to human dignity. This situation meant that Marianna was coming face to face with difficulties that could have been removed if there was a system in place to truly support her. As Moriña argues, Universities have tried to put in place a number of measures to support disabled students as more arrive, however “the existence of these actions is insufficient to ensure the right of the students to quality education, without discrimination and based on the principles of inclusive education.” ([Moriña, 2017, 5](#_ENREF_33)). What is really at stake is not just paying lip service to disabled students in HE but actually making sure they have the same chances to succeed as non-disabled students.

Some of these issues could start to be tackled with the help of proper legislation and other structural changes. Since there is no overarching legislation governing the access needs of disabled students in higher education in Portugal, any kind of regulation that is made is usually written by each University and passed into law by the power of each University’s legislative body (usually called the Senate in Portugal).

An analysis of the Statute for Students with Special Educational Needs from two of the major Universities in Portugal, the University of Porto and the University of Lisbon, points to a wording that reflects an individual and medical model of disability and sees impairment as a personal ‘problem’ (["Estatuto do Estudante com Necessidades Educativas Especiais (EENEE) da Uiversidade do Porto," 2008](#_ENREF_11); ["Estatuto do Estudante com Necessidades Educativas Especiais(EENEE) da Universidade de Lisboa," 2012](#_ENREF_12)). For instance, these often talk about disabled students as ‘experiencing difficulties in the learning process’ and see the role of the University as generously attempting to ‘help’ these students. (["Estatuto do Estudante com Necessidades Educativas Especiais (EENEE) da Uiversidade do Porto," 2008:1](#_ENREF_11)). Another major problem is that one does not even find in these statutes the concept of reasonable adjustment, which is prevalent in disability legislation in Britain or the United States of America. As problematic as the concept of ‘reasonable’ might be to some ([Lawson, 2008](#_ENREF_27)), the notion of adjustment has been crucial in disability rights legislation. The fact that such philosophy is not even present in these statutes gives us a strong indication of the kind of approach that underpins them and the possible consequences for students. Students who have a chronic illness and whose impairment might be undistinguishable may find it even harder to obtain proper adjustments, as Mariana mentions:

The other students who were also being supported by the office for students with special educational needs were blind or used a wheelchair so they had visible disabilities. The problem with our illness is exactly that it is not visible. There is a lot more... I wouldn’t say there is more discrimination towards us but it’s a different kind of discrimination. People can’t see what you have. I don’t know if I would prefer the other situation, it is perhaps even a bit absurd to even consider that. I think when [the impairment] is visible people will probably seek some kind of protection from it. We [people who are not visibly disabled] have that protection. I remember during many years I wanted it to be visible so that I could feel validated. Obviously these two situations have negative aspects. (Mariana, Female, Portugal, 31-40, Fibromyalgia, Chronic Fatigue Syndrome)

Mariana’s insightful discussion of the different issues faced by people with visible and invisible impairments is important to consider in the context of providing reasonable adjustments to students and tackling disablism. Disabled people who live with very visible impairments often have to manage a series of micro-aggressions, including other people’s reactions to disability as well as an alarming rate of hate crime ([Ralph, Capewell, & Bonnett, 2016](#_ENREF_37); [Tyler, 2013](#_ENREF_46)). Studies show that disabled people who have visible impairments will often be targets of abuse, violence, street harassment and other types of difficult situations ([Roulstone, Thomas, & Balderston, 2011](#_ENREF_38)). An important recent study in Portugal has documented alarming rates of violence against disabled women and girls in particular ([Campos Pinto, 2016](#_ENREF_7)).

People with chronic illnesses and other invisible impairments, as Mariana acknowledges, are sheltered from these types of uncomfortable and difficult immediate encounters with strangers. However, they face other types of challenges that are important to understand. They might, as Mariana also suggests, experience difficulties having other people acknowledge that they do experience barriers and that they do need reasonable adjustments. On the other hand, people who live with invisible impairments can experience other types of issues such as the expectation that a person that appears to be non-disabled ‘should’ act as if they are not disabled. Furthermore, the research has also suggested that because people living with chronic illnesses can be read as ‘non-disabled’ by others, they are often asked to conform, act and behave as a non-disabled person. As Mariana mentions, her understanding was that her professors had difficulty dealing with the access needs of someone who did not look visibly disabled and who had a condition that people probably knew very little about. These are important considerations to have in mind for professionals working in higher education settings.

 I would offer that the binary established by Western modernity between disability and ability still perceives the former as having particularly fixed characteristics (i.e. someone being completely incapacitated ([Wendell, 2001](#_ENREF_50)) or having particular types of impairments), whilst it sees non- disabled people as completely fit and able. People living with impairments that may not be visible to others defy this binary as they may be able, at different times, to inhabit both spaces or circulate through them.

The experience of disablism for people who live with chronic illnesses was unfortunately confirmed by many other accounts I received from participants in this study who focused on other aspects of their lives such as employment or interaction with others. For instance, the research concluded that many people experience serious forms of disablism when it comes to social benefits and social care. In both England and Portugal people had reported that access to necessary benefits was increasingly more difficult or not available (in the case of Portugal). In what relates to employment, participants also reported experiences of disablism for instance when it comes to employers not accommodating their needs or not believing their illnesses were real.

1. Chronic Illness and Ableism

Whilst situations of disablism similar to the one highlighted above, mean that disabled students can face particular kinds of barriers and obstacles in education, this paper also aims to highlight subtle, more hidden interactions that can have a real effect on a student’s experience but that are perhaps harder to acknowledge and challenge.

In this section, then, I will focus on Jane’s account and use this as an anchor point to highlight some of the issues that can be faced by some students, even when good institutional support and good reasonable adjustments might be in place. Jane is a British student in her twenties living with M.E. and C.F.S, she was keen to focus her account on her progress in higher education and how this experience had been for her:

After college I went on to study at my local university for 4 years and now in the middle of a postgraduate degree, but in the past 4-5 years my health has gone downhill again, I can get exhausted from a 3 hour practical and then feel too tired to attend lectures the next day. Luckily my lecturers are supportive and understand I get tired, but a lot of the students aren't so supportive and often comment saying I'm not taking my course seriously or I'm taking it as a joke. (Jane, Female, England, 21-30, Myalgic Encephalopathy, Chronic Fatigue Syndrome)

When I asked Jane about the level of support she had been able to obtain from the University, she was adamant that she had had access to good practices and had received good reasonable adjustments. Jane experiences issues attending lectures sometimes but she found that her lecturers would be happy to email her and let her know what was said and she also felt welcomed to go see them in person to discuss what she might have missed. She reported that she had been granted extensions for her coursework at times when she was having a more difficult time with the symptoms of her illness. She had also been given alternative exam conditions which meant she would sit her exams in a separate room, she was allowed to have rest breaks every hour, leave the room supervised if she was not feeling well and she had also had access to extra exam time. Her support package tailored by her university seemed to be quite targeted to her particular needs and considerate of the fact that her symptoms could fluctuate and change quite a lot. Her account also seems to suggest that her lecturers had some understanding of her circumstances and responded adequately. When asked if she considered that she had had proper support she was adamant:

Absolutely! I couldn't have asked for better support, it was much better than what I expected. If I hadn't had this level of support I don't think I would have been able to finish university or sit exam! (Jane, Female, England, 21-30, Myalgic Encephalopathy, Chronic Fatigue Syndrome)

Jane also believes the support she was able to obtain was the only reason she was able to finish her degrees. In her case, then, the disability legislation available in England to support disabled students seems to have been beneficial and was reportedly properly put in place by her institution, which enabled her to have access to University on equal terms with others.

 In England it is against the law for schools to treat disabled students unfavourably and, therefore, institutions are required to make reasonable adjustments to prevent disabled students from being discriminated against (["Equality Act 2010,," 2010](#_ENREF_10); [Gov.UK, 2015](#_ENREF_18)). This involves both changes to physical structures whenever necessary (making sure buildings are accessible, etc) as well as providing extra support and aids (such as specialist teachers or additional equipment required) ([Gov.UK, 2016b](#_ENREF_20)). These provisions are defined in the Equality Act, which came into effect in October 2010, as well as the SEND code of practice 2014 (["Equality Act 2010,," 2010](#_ENREF_10); [Gov.UK, 2015](#_ENREF_18)),.

 At the time when Jane was attending higher education in England there was also another essential layer of support that students in England could access. This was a financial help called Disabled Students’ Allowance (DSA) and it allowed disabled students to buy goods or services that are necessary to access education on equal terms with other students ([Gov.UK, 2016a](#_ENREF_19)). For instance, disabled students could buy computers or software or hire specialist helpers such as note takers or readers. In April 2014 the government announced significant changes to the DSA but the old rules were still in place at the time Jane’s account was submitted ([Willetts, 2014](#_ENREF_51)). The importance of these several layers of support cannot be underestimated. Jane considers the existing support options worked well for her and her account does seem to indicate these were decisive factors that contributed to Jane’s ability to succeed at University. These layers of support seem to have removed some of the access barriers that Jane might have experienced otherwise. This is not to say that this would always be the case, in fact, many studies that focused on the experiences of disabled students in HE demonstrate that they experience a myriad of barriers in the UK. ([Fuller, Healey, Bradley, & Hall, 2004](#_ENREF_15); [Holloway, 2010](#_ENREF_25); [Madriaga, Hanson, Kay, & Walker, 2011](#_ENREF_29); [Vickerman & Blundell, 2010](#_ENREF_48)).

 However, what is also interesting about Jane’s testimony, is her mention of how her colleagues reacted to her and her impairment. It was her impression that many of her peers assumed and told her she was not taking her course seriously. When I asked Jane to elaborate on this point, she mentioned:

In my class there are roughly 20 students. Some are understanding of my illness, others are not! And the strange thing is it's the people I am more in contact with that don't understand! Some people in the class are asking how I am . . . especially if I’ve been absent a while. They will take notes for me and tell me what I’ve missed. Whereas the people I 'hang around' with they won’t get me class notes, or let me know what was said they're usual response is ‘you should have gone to the lecture’.  I was supposed to go to a revision session last week, but I wasn't well enough to attend and I asked one of them how it was, any useful hints etc and they said ‘It was good, you should have been there’. They seem to think I take Uni as a joke, and therefore won’t help me. They don't think I should pass my exams because of my attendance, I try to explain to them about my illness and one of them just said that you had to push yourself to do things and not think about it. So basically telling me it's all in my head! It sometimes makes me want to give up as I have no support from so called ‘friends’. . . . Luckily lectures are over now, I just have exams and a dissertation and so I don't have to deal with these people anymore. (Jane, Female, England, 21-30, Myalgic Encephalopathy, Chronic Fatigue Syndrome)

Jane’s account seems to indicate that even in cases where people may find an appropriate framework of institutional support, students may have to tackle a set of other complex issues which are about people’s attitudes and believes towards disability and what one could term ability-diversity. The lack of understanding Jane reports was one of the most common issues reported by participants in this research regarding other aspects of their lives. For instance, participants reported difficult personal interactions with family and friends as well as lack of understanding from others in professional and institutional settings. The general lack of knowledge and acknowledgement around these illnesses is a significant contributor to participants’ distress in everyday interactions as, at its core, it means a disavowal of a person’s bodymind ([Price, 2011](#_ENREF_35)) and symptoms. One could classify such disavowal as an ontological one because it affects the core of a person’s being, who they are and how they perceive themselves. To dismiss someone’s bodymind claims is to refuse a mutual relationship where both people come together on equal terms, since the disavowal means one person is imposing a particular framework of understanding on the other person. It also means the imposition of understandings of bodyminds that are usually framed by a person’s own experience instead of trying to empathize with the other and what they might be feeling as well as what that might mean for the other person. Even though it may seem that these interactions and what they represent may not be significant, they represent a succession of micro-aggressions that are likely to create an effect for those who are on the receiving end. If these prove to be hard and difficult in personal relationships (where partners or best friends may downplay the importance of how someone is feeling a particular day or indeed not offer the least understanding in regards to people’s reported symptoms), they are not any less distressing in institutional settings. Even though it can be argued that it’s someone prerogative in all cases to not offer help and support or their notes for someone else when they miss a class, Jane reports that such interactions were always difficult for her because they were often marked by an accompanied commentary of why Jane did not merit her colleagues’ class notes or why she should not deserve to pass due to her attendance.

I want to argue that these instances are related to the ways ableism works and its effects on daily interactions. I am interested in what this account tells us about the inner workings of ableism since these aspects are not so much a product of architectonical or access barriers but rather cultural underpinnings of the way people relate to disability. Unlike Mariana’s account previously, Jane’s reported difficulties are not related to basic lack of access needs not being met or lack of reasonable adjustments. Rather, they are anchored in a system of ideas and beliefs that, in this case of chronic illness, disregards the report of embodied symptoms as relevant or believes that such reported symptoms are not, as Jane puts it, ‘real’. Again, this accounts for a fundamental ontological disavowal of who people are and what matters to them. I argue that this is also a system of beliefs that can only conceive of limited amounts of minds and corporality who are expected to act, behave and approach others in a set and limited manner. Therefore, when this expectation is not met, the chronically ill body can be seen as being defiant of expectations and when it is not possible for others to make it act in the expected manner, the usual response seems to be to question it.

Ableism relies on dichotomous systems of thinking inherited from Western Modernity. It could be argued that a particular manifestation of this kind of thinking would be the association of disability with only specific kinds of impairments that are imminently visible, thought of as stable, and seem easy to categorize. Jane’s impairment fluctuates quite a lot and this means it does not neatly fall into a perceived category.

A recurrent theme in many of the narratives I received which is also present in Jane’s account relates to what she identifies here as one of her peer’s advice to ‘push yourself to do things and just not think about it’, despite the illness. Other participants, in the context of personal interactions, report statements of this kind in their interaction with others. I want to argue that such interactions can be read as clues about underlying cultural assumptions on illness and disability. On the one hand, they present a disavowal of the person’s embodied experience and, on the other hand, they bring about a harsh judgement about one’s abilities. Participants often perceive these encounters as statements that seem to be implying that if one simply tries ‘hard enough’ one can achieve things. This cultural disavowal of people living with chronic illnesses also seems to bring with it the assumption that reasonable adjustments are not actually required for these people, since they *seem* *to not fit* the cultural disability mould of what our culture assumes disability is. However, as Jane’s story illustrates, the institutional support and accommodation she reports being able to obtain, and the fact that it worked well for her, was crucial to her success.

Looking specifically at ableism allows us to uncover the expectations around ability performance. To some extent, Jane’s account provides a good example of how ability is a performative expectation that we all take part in at some point, unless we become aware of it. It is about the core belief that bodyminds need to be pushed and rushed, directed and corrected, instead of their rhythms being respected. It is about, even without realizing, commenting on someone’s rhythms and needs. It is about nudging people to not complain, to not share how they feel, to not ‘bother’ others with their bodyminds. In this sense, it is profoundly political work to uncover and challenge such notions.

1. Conclusion

In this article, I have tried to use two case studies of students who live with chronic illnesses to illustrate how both disablism and ableism can shape and affect the experiences of some students in education. Whilst the impact of disablism has been somewhat well documented in disability studies, here I offered an understanding of the sort of barriers students living with chronic illnesses can experience in Higher Education, particularly in settings where lack of legislation and cultural awareness might exacerbate such barriers. It is important that we keep tackling access barriers that continue to mean some students will be at serious disadvantage. The case of Portugal demonstrates the need for supportive legislation to be in place that understands the importance of reasonable adjustments and other measures. Mariana’s account highlights how the presence of access barriers can significantly impact and disadvantage a student.

Jane’s account, on the other hand, offers an insight into how the norms and codes that shape our understanding of dis/ability can also have a direct impact in people’s lives. It could be argued that, similarly to other overarching systems of domination, we are all framed by such norms and codes. We all respond to the neoliberal work ethic that tells us to push ourselves to the limit and not show vulnerability or not share our bodyminds with others because they might interpret this as complaining or seeking sympathy. Beginning to identify such mechanisms is the first step to offering a different possibility of interaction and being.

References

Andrews, M., Squire, C., & Tamboukou, M. (Eds.). (2008). *Doing Narrative Research*. London: SAGE.

Barden, O. (2012). “...If we were cavemen we'd be fine”: Facebook as a catalyst for critical literacy learning by dyslexic sixth form students. *Literacy, 46*(3), 123 - 132.

Barnes, C. (2012). Understanding the Social Model of Disability: Past, Present and Future. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. xvi, 452 p.). London: Routledge.

Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge: Polity Press.

Beckett, A., Ellison, N., Barrett, S., & Shah, S. (2010). ‘Away with the fairies?’ Disability within primary‐age children's literature. *Disability & Society, 25*(3), 373-386. doi:<http://dx.doi.org/10.1080/09687591003701355>

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

Campos Pinto, P. (2016). Out of the shadows: Violence against girls and women with disabilities in Portugal. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap, 10*(2), 137-147. doi:<http://dx.doi.org/10.1016/j.alter.2016.03.009>

Decree-law n.º 3/2008, Pub. L. No. 3/2008 (2008 7th of January).

Duffy, B. (2005). The Analysis of Documentary Evidence. In J. Bell (Ed.), *Doing your Research Project: A Guide for Firs-time Researchers in Education, Health and Social Science* (4th Edition ed., pp. 122-133). Maidenhead: Open University Press.

Equality Act 2010,, Pub. L. No. Chapter 15 251 (2010).

Estatuto do Estudante com Necessidades Educativas Especiais (EENEE) da Uiversidade do Porto, 5 (2008).

Estatuto do Estudante com Necessidades Educativas Especiais(EENEE) da Universidade de Lisboa, (2012 June 1, 2012).

Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Frank, A. W. (2010). In Defence of Narrative Exceptionalism. *Sociology of Health & Illness, 32*, 665–667.

Fuller, M., Healey, M., Bradley, A., & Hall, T. (2004). Barriers to learning: a systematic study of the experience of disabled students in one university. *Studies in Higher Education, 29*(3), 303-318.

Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction*. London: SAGE.

Goodley, D. (2014). *Dis/ability Studies: Theorising Disablism and Ableism* New York: Routledge.

Gov.UK. (2015, 1st of May 2015). SEND code of practice: 0 to 25 years. Retrieved from <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Gov.UK. (2016a). Disabled Students' Allowances (DSAs). Retrieved from <https://www.gov.uk/disabled-students-allowances-dsas/what-youll-get>

Gov.UK. (2016b). Guide to Disability Rights. *Gov.UK.* Retrieved from <https://www.gov.uk/rights-disabled-person/education-rights>

Grbich, C. (2007). *Qualitative Data Analysis: An Introduction*. London: SAGE.

Grinyer, A. (2002). *Cancer in Young Adults: Through Parents’ Eyes*. Buckingham: Open University Press.

Ho, A. (2004). To be labelled, or not to be labelled: that is the question. *British Journal of Learning Disabilities, 32*(2), 86-92. doi:10.1111/j.1468-3156.2004.00284.x

Hodkinson, A. (2012). Inclusive education and the cultural representation of disability and disabled people within the English education system: the influence of electronic media. *Journal of Research in Special Education Needs, 12*(4), 252 -262.

Holloway, S. (2010). The Experience of Higher Education from the Perspective of Disabled Students. *Disability & Society, 16*(4), 597-615. doi:10.1080/09687590120059568

Jupp, V., & Norris, C. (1993). Traditions in Documentary Analysis. In M. Hammersley (Ed.), *Social Research: Philosophy, Politics and Practice* (Vol. SAGE, pp. 35-51): London.

Lawson, A. (2008). *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* Oxford: Hart Publishing.

Long Term Conditions Team. (2012). *Long Term Conditions Compendium of Information, Third Edition*. Retrieved from <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf>

Madriaga, M., Hanson, K., Kay, H., & Walker, A. (2011). Marking-out normalcy and disability in higher education. *British Journal of Sociology of Education, 32*(6), 901-920. doi:10.1080/01425692.2011.596380

Mallet, R., & Runswick-Cole, K. (2014). *Approaching disability: Critical issues and perspectives* London: Routledge

McCullock, G. (2004). *Documentary Research in Education, History and the Social Sciences* New York: Routledge.

Milligan, C. (2005). Placing Narrative Correspondence in the Geographer’s Toolbox: Insights from Care Research in New Zealand. *New Zealand Geographer, 61*, 213–224.

Moriña, A. (2017). Inclusive education in higher education: challenges and opportunities. *European Journal of Special Needs Education, 32*(1), 3-17.

O'connor, M. (2007). Documentary Analysis and Policy. In J. M. Addington-Hall, E. Bruera, I. J. Higginson, & S. Payne (Eds.), *Research Methods in Palliative Care* (pp. 229-244). Oxford: Oxford University Press.

Price, M. (2011). *Mad at School: Rhetorics of Mental Disability and Academic Life*. Ann Arbour: University of Michigan Press.

Prior, L. (2003). *Using Documents in Social Research*. London: SAGE.

Ralph, S., Capewell, C., & Bonnett, E. (2016). Disability hate crime: persecuted for difference. *British Journal of Special Education, 43*(3), 215-232. doi:10.1111/1467-8578.12139

Roulstone, A., Thomas, P., & Balderston, S. (2011). Between hate and vulnerability: unpacking the British criminal justice system’s construction of disablist hate crime. *Disability & Society, 26*(3), 351-364. doi:10.1080/09687599.2011.560418

Scott, J. (2006). *Documentary Research*. London: SAGE.

Squire, C. (2008). Experience-centred and Culturally-oriented Approaches to Narrative. In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing Narrative Research* (pp. 41-63). London SAGE.

Squire, C., Andrews, M., & Tamboukou, M. (2008). What is Narrative Research? In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing Narrative Research* (pp. 1-21). London: SAGE.

Thomas, C. (1999). *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Thomas, C. (2007). *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave Macmillan.

Titchkosky, T. (2007). *Reading and Writing Disability Differently: The Textured Life of Embodiment*. In (pp. xiv, 250 p.).

Titchkosky, T. (2011). *The question of Access: Disability, Space, Meaning*. Toronto: University of Toronto Press.

Tyler, I. (2013). *Revolting Subjects: Social Abjection and Resistance in Neoliberal Britain*. London: Zed Books.

UPIAS. (1976). Fundamental Principles of Disability. In. London: Union of the Physically Impaired Against Segregation.

Vickerman, P., & Blundell, M. (2010). Hearing the voices of disabled students in higher education. *Disability & Society, 25*(1), 21-32. doi:10.1080/09687590903363290

Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections On Disability*. New York Routledge.

Wendell, S. (2001). Unhealthy Disabled: Treating Chronic Illnesses as Disabilities. *Hypatia, 16*(4), 17-33.

Willetts, D. (2014, April 7, 2014). Higher Education: Student Support: Changes to Disabled Students' Allowances (DSA). Retrieved from <https://www.gov.uk/government/speeches/higher-education-student-support-changes-to-disabled-students-allowances-dsa>

Wolbring, G. (n.d.). Ableism, Disability Studies and the Academy. Retrieved from <http://www.ideas-idees.ca/blog/ableism-disability-studies-and-academy>