The additional labour of a disabled PhD student

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The additional labour of a disabled PhD student - by Stephanie Hannam-Swain

Abstract

This is a personal account of the challenges I have faced during the first year and a half of my PhD, solely due to my identity as a disabled student. I address issues such as a lack of representation when researching PhD life, the impact of the services which are meant to be there to help and the complexities of juggling the additional time consuming events which occur when you are disabled, with PhD time, a home life and work. This is especially relevant in the UK at this time, as the Disabled Students Allowance has recently been cut back, meaning there is less support available for disabled students, and with the increased marketisation of Higher Education it could be argued that there is less impetus for Universities to support those who have non-standard needs.

Keywords: PhD life, additional labour, disabled student, disabled student services, personal assistants

In this paper I aim to highlight the extra labour that I face purely due to my status as a disabled PhD student. I highlight the impact of the often unseen and unspoken about secondary consequences of the main impairment and also the contradictory nature of the services which are sold to students as being there to help. This is not an attack on a particular university, as speaking to many other disabled PhD students they have experienced very similar things all across the UK. I would also like to praise my two supervisors for the huge amount of help, advice and time given to me in exploring these issues.

Perhaps unusually I am going to start by giving a little context by including some information about myself. I am in my early thirties and a lifelong full-time wheelchair user due to my impairment, Brittle Bones. My unconventional body makes me unable to 'pass' as non-disabled partly as I am under four feet tall, but things that I struggle with, like heavy doors, carrying bags and fatigue are often less obvious unless people are explicitly told. I do my PhD part-time and I work part-time, whilst living at home with my mum who was a nurse. I grew up with no knowledge of the medical or social model of disability - something I have come to learn about only in the last five years or so, and in most things I have always tried to be as non-disabled and independent as possible, in an attempt not to 'hassle' people or cause too many 'problems'. I would say that only my parents truly understand how much support and help I need.

During my time as an Undergraduate I had full time support at University provided by mum. A few years later, mostly because I only needed to be in for a day at a time and if I was lucky half a day, I used the 'non-medical' support offered through Disabled Student Allowance (DSA) whilst I completed my Masters. Although mum often suggested that one day I should get my Doctorate, I wasn't enthralled by the idea until about 6 months before the end of my MSc. I was developing an area of

interest and I could see a clear gap in knowledge. I was discouraged though by all the problems that I could envisage and this wasn't helped by a lack of disabled representation in literature and websites which dealt with PhD students' experiences of the process. I was looking for 'Own' support, which Goffman (1963) propositions as a valuable source of support and encouragement from those who share a stigma. I wanted to hear from people who were in a similar position to me disability wise, who had gone through and gained a PhD. More recently I have found PhDisabled and Chronically Academic which are online areas for disabled people with a range of impairments to share their experiences.

As soon as I received my offer I re-applied for DSA which as Riddell and Weedon (2014) acknowledge, is a lengthy process which involves obtaining medical certificates and going to assessments of need, even if you were a student at the university just a few months beforehand and your condition has not changed. At the assessment, because the cuts to DSA had just come into force, the assessor seemed very unsure about what level of support I would be granted and she explained that because the PhD process was so different to undergraduate and taught Master's courses they had developed their own assessment just for the purpose. Unfortunately this involved asking me a lot of practical questions about my particular PhD, which as I hadn't started yet I couldn't answer. I came out of the assessment feeling anxious and unconfident that everything would be properly addressed.

The first issue that was identified was access to the areas which PhD students are allocated a desk to work. I was unable to access any of these areas independently but once my choice of location was confirmed the university did arrange for electric door openers to be fitted. The problem with these is, as with all technology, they fail and it seems these fail pretty often. I lost about a month of PhD time at the start waiting for these to be fitted, and since then because they have broken down suddenly, I have had to go back home and write off numerous days due to it being unsafe for me to be in a room alone which I was not able to exit. My colleagues were really good and helped as much as they could, often staggering when they left the room so that I wouldn't be alone but I felt disempowered and that it put unnecessary pressure on budding academic and personal friendships. I also felt that it was better for me to withdraw from the situation and reduce the 'obtrusiveness' Goffman (1963, pg 66) of my impairment. One option is to have a non-medical support worker with me, supplied through DSA, but you need to give about a weeks' notice to book these and of course technology doesn't give me a week's notice of its impending failure. To have a PA with me constantly, whilst for the most part I sit at my desk working on the computer, brings with it its own problems in terms of feeling like I need to be sociable and provide them with a 'proper' reason to be there.

The DSA system itself is something which has given me the biggest headache, especially alongside council systems for direct payments. The process has been extremely longwinded and stressful and at times I have considered giving

up on the whole thing as I didn't see a way forward. Due to the unpredictability of my condition I could fracture at any point - no trauma needed. This means that ideally I need someone with me at all times or 'on call'. As I've mentioned DSA does provide non-medical support, if booked in advance, but the support workers are not allowed to do anything which could be classed as personal care. This is especially pertinent to me when I am away from university grounds, at conferences, as they would not meet my needs. I already knew this rule, and so I enquired as soon as I was accepted to do my PhD, to the council for Direct Payments. I was hoping that they would give me enough hours so that I didn't have to use DSA support at all. However with the budgets being so tight, they would only give me enough hours to cover me for the personal care that I need. This means that technically I should have a DSA PA with me for most of the time and a direct payments PA with me for when I need the loo. At conferences I should take both with me and they should each have separate roles. I find this entirely unworkable and ludicrous. On top of this, the university has told me that my DSA PA would be unable to travel to the conference with me in my car, meaning that we either have to go separately and I would have no support whilst traveling out of the city, or we travel on public transport which would initiate panic attacks. After a lot of pushing I was told that it's due to their 'lone working policy'. There was no negotiation available even when I pointed out to them that this situation would leave me at a disadvantage and that there are ways of keeping their workers safety paramount whilst working alone with a student. However I was left feeling that despite this being a major access issue, my own health and safety was disregarded within a university and DSA system which seems to only be able to cater to needs which are deemed acceptable. The university's position that it was not reasonable for me to expect this alteration because it could put their workers at risk is a common justification narrative that people often take when defending accessibility issues within organisations. Titchkosky (2008, pg43) calls this type of defence a "sensible say-able" which serves to make their lack of accessibility ordinary and discourages challenge from the disabled person.

All in all it took over a year from the start of my Direct Payments application to be in a position where I could employ someone, due to many delays, assessments not being carried out properly and care plans not being written properly or explained. I now have two lovely undergraduate students who come in as and when I need them (depending on their timetables) and support me when I am only away from campus for the day, if it's longer I take my mum. I am very aware that I will have to give up more of my PhD time for reviews of my needs and financial assessments again in the near future and I have spent hours in forums learning how the system works, learning how to be an employer and learning employment law, again because the council does not provide you with any practical help with this.

Although my main impairment makes me visibly disabled, an identity which I mostly embrace, I do often have the choice about letting some of the secondary consequences also be part of my identity. As Watson (2002) has argued, choosing

to identify as disabled can be useful in terms of accessing support but to choose not to can help to avoid discrimination and stigma. This choice is something which Riddell and Weedon (2014) mainly attribute to students with invisible disabilities however I find that I also tend to choose not to disclose the secondary consequences of my disability in an effort to not present as 'too disabled'. As a consequence this can lead to problems such as people not understanding the true impact of certain situations or the impact that their expectations have on me. As I stated earlier fatigue often plays a part in my life, and this is something which is not obvious to someone who doesn't know me really well or who doesn't know the condition very well. I often try to ignore it and push on through, to achieve the things that I want to, that are expected of me and to adhere to the 'normal' timeline of life events or academic schedules and policies. The problem with that is that if I do keep pushing myself, I am at higher risk of fracturing a bone - which can leave me physically unable to attend university, go to work or to do any work at home for days or even months at a time. Even if that doesn't happen the exhaustion can get to the point of being cognitively unable to do anything productive for a couple of days. This hasn't been helped by the many nights I have laid awake at night over the past 2-3 years, worrying about when it is my turn to be called for my PiP assessment and what impact it will have on my life if that doesn't go as I feel it should. After years of trying to be as non-disabled as my body would allow, here I will be expected to talk openly and fully about all of the things that I can't do and to embrace my 'true' disabled self in full, or fail to meet the increasingly narrow definition of 'disabled enough' to get the help that I need.

Just like anyone I also have to strike a reasonable work/life balance to include spending time at home, with friends, at work and working on the PhD. Due to the condition I have though, just like many people with any chronic condition, I have additional things that I have to find time for such as hospital appointments. Recently I fractured a rib and it kept re-fracturing because I didn't take the necessary time to recover properly, in the end this resulted in my body forcing me to stop for three days and do nothing, meaning that I had to take time off work and the PhD. My car is heavily adapted for me to drive from my wheelchair, this of course means that it can and does fail leaving me unable to access university or work which then leads me to having to work time back for my employer, losing more PhD time in the process. I'm in the same situation if my wheelchair fails me. I have just got a new car but a feature was forgotten and so soon it will be taken off me for a week. There are options available to keep me on the road, but I feel I cannot use these as I do not feel they are safe for me.

Overall, I am very much enjoying the PhD process and I am grateful for the help and support that is out there. I am privileged enough to be enjoying some amazing experiences throughout the process and despite all the things that I have spoken about I wouldn't want to give up on it, however I can't get away from the

feeling that having a disability means that I am attempting to do a PhD with an extra workload which is equivalent to having another part-time job.

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