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“Everyone Thought My Library Assistant was My Mum”. Visually Impaired and Blind Students’ Experiences of Interactions with Support and Other Staff in Higher Education

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Abstract

This article explores visually impaired (VI) and blind students’ experiences of support as an undergraduate student in UK higher education (HE) by focusing specifically on relationships and interactions between VI and blind students and support staff within Higher Education. Participants within this research show how their experiences highlight an uneven and often exclusionary Higher Education landscape. Constructions of disability and impairment show a complex relationship between support provision as it is offered and experienced. The findings overall suggest the experience of support is more than the placing together of student and support worker and concerns the management of this relationship, particularly around underlying assumptions about being VI. Support is not unnecessary or unwelcome, instead, the complexity of the relationship, the additional work associated with support experienced by these students, combine to shape academic experience.

Keywords

visual impairment – higher education – disability – ableism

Introduction

Background

This article explores the support experienced by visually impaired (VI) and blind undergraduate students in UK higher education (HE). The article focuses on relationships and interactions between these students and the support staff within their Higher Education Institution (HEI). Underlying constructions of disability and impairment related to a lack of choice and autonomy for participants, particularly in relation to the experience of the provision of support, show a complex relationship. A key issue suggests there is more involved than the placing together of student and support worker and concerns the management of this relationship, particularly around underlying assumptions about being VI. Unpacking this indicates “the complex cultural ways in which bodies are shaped by and shape the socio-cultural conditions in which they emerge” (Goodley and Runswick-Cole 2013:15) and offers an alternative understanding of the ethos of support provision. Support is not unnecessary or unwelcome, instead, the complexity of the relationship, the additional work associated with support experienced by these students, combine to shape academic experience.

Disabled students who identify support requirements are obliged to participate in a formalised, professionalised assessment of ‘need’. The conceptualisation of normativity is distinct and early on places students within a medicalised gaze of loss, limitation, vulnerability, and inability. As Hutcheon and Wolfbring (2012: 46) note “the presumption of disability as biomedical in nature tends to shape the process such that evidence of disability ... is required to receive services”.

That the Disabled Students Assessment (DSA) process is moving from a historical reliance on a medicalised process to more of a social model (Office for Students: 2019) suggests some recognition of a disconnect between HE and the disabled community. This was voiced by Barnes (2007) who noted the importance of ensuring HE produces meaningful, well-informed knowledge built upon the experiences of disabled people. HE previously has not been specifically included in legislative structures to tackle unequal access, and whilst arguably there is some limited address of this within iterations of policy rhetoric, there remain challenges to equal access. In the academic year 2019/20, 368,816 disabled students studied in UK HE, around 15% of total student numbers (HESA: 2021) As of 2018/2019 there were 3,170 students registered as identifying as VI or blind (HESA: 2021), suggesting a statistically underrepresented cohort. These figures suggest a need for a focus on the understanding

of experience such as the underlying assumptions about what VI and blind students need in relation to support.

Medicalised understandings of what support is needed are rooted in notions of lack, drawn from assessment, and rely on management of the deficit between constructed binary opposites; non-disabled and disabled students or, those who require support and those who do not. Existing literature exploring the experiences of disabled students more generally (Jacklin 2011; Vickerman and Blundell 2010; Jacklin et al 2007; Fuller et al 2006) or focusing down specifically on the experiences of VI and blind students in singular contexts (Bishop and Rhind 2011; Tinklin and Hall 1999), shows that access and participation in HE remains convoluted and uneven. Significant obstacles often relate to, but are not limited to, physical access issues (Van Jaarsveldt and Ndeya-Ndereya (2015), access to resources (Croft 2020), engagement with the physical environment (Beauchamp-Pryor 2011; Bishop and Rhind 2011), peer interactions and relationships with academic and non-academic staff (Van Jaarsveldt and Ndeya-Ndereya 2015; Jacklin et al 2007; Fuller et al 2004). Impact on student participation is multifaceted and can significantly constrict a sense of belonging, limit access to physical classrooms and resources, promote inequality amongst peers and negatively influence individual wellbeing (To be added after publication).

Not Belonging

I note in (Croft 2020), that students narrate a sense of *not* belonging predicated on an alikeness of impairment (Bolt 2005) and tensions around everyday participation. VI is understood through distinct notions of sighted and non-sighted, an understanding which Bolt (2005) notes as the homogeneity of a construction of 'the blind', suggesting that presupposed similarities are applied to all VI and blind persons. This understanding, he contends, is one which is "antithetical to the sighted, deviant in relation to an assumed normalcy" (Bolt 2005: 4). Notions of the alikeness of impairment may not just hang on medicalised understandings, but also on widely held 'common sense' ideas that impairment is unwanted and unwelcome. These representations present challenges for those who question the status quo, such as those who present within environments typically appropriated for non-disabled people.

Participants interacted with multiple HEI departments as they studied, such as welfare or disability support (DS), library and other support services. Whether residing in student accommodation or living away from campus, participants encountered support and student services staff from all university departments. Job titles may differ dependent on university structure, however most offer structurally similar interactions to students. In research with VI

students and HEI support service staff, Hewett et al. (2017) note VI students felt that the ways in which they experience interactions with these staff differed to students with less significant visual impairment. This was described as based in the actions and reactions of staff members, with one participant noting some staff fear when working with students with a significant visual impairment (Hewett et al. 2017). Bishop and Rhind (2011: 194) state the "greatest barrier of all may be the ingrained and resistant attitudes of individuals both within and outside of HE", suggesting interactions with support staff may be influenced by existing preconceptions, understanding and expectations around VI and blindness. This highlights the importance of understanding implications, development, and management of the relationship between support worker and student.

Hewett et al. (2017) note an unpreparedness regarding making accommodations for VI students which may highlight how VI and blindness are understood within HE. These understandings, perhaps inevitably, consider the individual in isolation by drawing on medicalised dichotomies of tragedy and deficit (Oliver 1990). These constructions may appear in interactions with HE, particularly via what Swain and French (2000: 573) note is a dominant understanding of visual impairment:

To become visually impaired, for instance, may be a personal tragedy for a sighted person whose life is based around being sighted, who lacks knowledge of the experiences of people with visual impairments, whose identity is founded on being sighted.

Ideas of loss and deficit create a normative position based on Shakespeare's (2014) suggestion of a continuum of visual impairment with "normal" ranges divided from and positioned at the other end of the scale to those deemed as not. As Titchkosky (2000: 207) states,

sight too is seen... as a condition interpreted as a given... those with the condition of eyesight are disturbed when they see blindness "because" they see that the other does not. Sighted others observe the blind person's gaze and find lack, difference, anomaly, and conspicuous oddness. Eyesight is the condition of normalcy, the expected, communicative and yet non-obtrusive fact of normal life.

Titchkosky shows us how dominant societal constructions consider sight as taken for granted, a prevailing position of assumed normalcy. Michalko (2002: 149) in discussing his experiences as a blind person, explores expectations of normalcy inherent in our interactions. He suggests:

Most important to the standard of normalcy, I can demonstrate that I know the standard and can act in it “standardly,” although I do it differently. In such ways as these I can show that, like everyone else, I am not everyone else, but I sure am “like them”. Like everyone else I can participate “like everyone else” even if I have to do it differently. It is important – to everyone else – that I do things like everyone else no matter how differently I do them, so long as I do them – like everyone else.

To be positioned as other within this reading of the ‘fact of normal life’ that possessing sight provides, inescapably constrains, and constricts, those who seek to challenge this by their attempts to participate in typically sighted pursuits. HE, like other pursuits which require adopting an identity within a consumer lifestyle (Hughes et al. 2005) presents a challenge for disabled people through homogenised assumptions.

HE currently inhabits a neoliberal ideological position focused on individual endeavour to achieve economic and social security. This requires a commitment to participation within HE structural systems aimed at securing a position as a viable, valuable, and productive member of society who requires little intervention or support. For disabled people, in HE and elsewhere, this often requires dual performed roles as both autonomous, objective individual and, simultaneously, dependent, vulnerable other. Potential and current students are required to act out these roles leading up to, and throughout, university study. As has been shown (Croft 2020; Hewett et al. 2017, Bishop and Rhind 2011) to access support, in all guises, disabled students must engage with processes set out for provision of DSA and are subject to relationships with academic and support staff. Alongside this they need to establish relationships with peers and navigate complex administrative procedures.

There are therefore significant barriers to participation and Hewett et al. (2017) note these can lead to the eventual withdrawal of students. Hewett et al. (2017) and Bishop and Rhind (2011) suggest these barriers take many forms, including absence of material in suitable formats, lack of opportunity to make changes to established practices and perceived barriers that preclude feelings of belonging and participation. Whilst those working within student support services are attempting to provide a quality service, complex and problematic constructions about visual impairment, gained through “textbooks of disability” (Titchkosky 2000: 198), often position the individual in deficit or as part of a homogenised, collectivised reflection as other. This again highlights the crux of this article; that bringing together student and support requires an in-depth understanding of the complexities of such a relationship and its impact on the student experience.

Methodology

This article seeks to expand existing literature by articulating the experiences of a small cohort of VI and blind students and relates some of the ways they experienced relationships with professionals working in a variety of roles in HE. Their accounts show that although their experiences varied, being identified as a VI or blind student profoundly influenced their interactions and affected their engagement. This was a diverse group in relation to age and gender, of whom three had recently completed academic programmes and were moving on to postgraduate or professional qualifications aligned to employment. The remainder had recently completed or were currently studying. All participants had experienced earlier statutory assessments and engaged with organisational disability services within HE.

Methodological Approach

A Grounded Theory (GT) approach aligned with the research ethos and offered opportunities for self-reflexivity (Charmaz 2014). Charmaz noted the need for researchers to be aware of their own, and participants' positionality, arguing that “the researcher and researched co-construct the data – data are a product of the research process not simply observed objects of it” (Charmaz 2008: 402). Rather than the researcher holding the position of power traditionally associated with research ‘done to’ disabled people, data discussed here was generated and understood in context, rather than as a decontextualized phenomenon. Braun and Clarke (2006: 9) contend this is “a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society”, a position which underpins the diverse experiences of the participants.

Challenging traditional concepts of research with disabled people as subjects ‘of’ research was crucial to the research process and underpins the methodological framework, centred on the ethos of ‘nothing about us without us’, thereby highlighting a core commitment to championing the rights of disabled people. In doing so it addressed a critical concern that research carried out with disabled people may simply further the interests of the researcher (Oliver 1990). Consequently, the research drew upon key ideas of emancipatory research which politicises and demands the promotion of rights within the research process. Whilst Mercer contends that emancipation is hard to define (2004: 129) he also argued that “emancipatory disability research must continue to explore disablist views of social reality and contribute to debates about how this knowledge can be used to overturn the social exclusion of disabled people”.

In successfully receiving ethical approval the researcher specified detailed informed consent; right to withdraw; anonymisation and use of future data. Participants' requests regarding the form materials used in the research took determined engagement, expressing a preference for email and follow up phone calls to discuss questions, and all gave consent prior to the research taking place. All were consulted across the research process regarding willingness to continue participation and were able to engage with the recorded data, both to provide transparency and to allow time for reflection about representativity of experience.

In line with the underlying ethos of the research, using a GT approach considered the construction of theory as an emergent process through data analysis and knowledge construction (Charmaz 2014). The research data was gathered and analysed iteratively; thus, data collection, analysis and eventual theory were closely affiliated (Denscombe 2010). Strauss and Corbin (1998) assert GT incorporates a deeper understanding of the data manifested through creative ways of asking questions, creating fittingly termed categories, and making comparisons. Analysis develops from the rigorous and creative interaction between researcher and data, moving back and forth to familiarise and reflect on the emerging findings, ensuring concepts and ideas are rigorously ascertained. The construction of relevant themes (Charmaz 2014) drew out the participants' key ideas shared in interview.

The aim of the research was not to develop an overarching theory or model, but to provide a way for a typically underrepresented group to share their experiences. As such broad research questions were developed:

In what ways do the paradigms of visual impairment and HE intersect and interact?

How do VI and blind students construct and describe their identity within HE?

In what ways is the concept of participation played out in relation to accounts of the experience of VI and blind students in HE?

Sampling

Participants were originally contacted via a purposive sample of VI and blind students in HE, known to the researcher, which developed through a snowball sample as participants shared information amongst their wider network of VI and blind peers. The research sought "the best information through focusing on a relatively small number of instances selected on the basis of their known attributes" (Denscombe 2010: 35).

Although, participants identified their own diverse backgrounds and current life circumstances, all identified as white UK residents, which, given the limited numbers, highlights a constraint in exploring the experiences of VI and blind students more broadly. Four identified as male from mid-20s to mid-40s; the remainder as female, from 19 to mid-20s. Participants identified individually as visually impaired, severely sight impaired or blind, as they felt appropriate, again in line with the underlying ethos of the research.

Data Collection

Participants developed a consensus that they would commit to two, up to two-hour long interviews within a period of six months as the reflection between encounters helped to create a unique record of their individual experiences.

General research prompts for data collection were loosely structured around topics chosen by the participants, for example relationships, accessing programmes of study and moving around campus. They described experiences they felt were indicative of their lives, reflecting Charmaz’s assertion that “the participant talks; the interviewer encourages, listens and learns” (2014: 57). Talk would therefore sometimes move beyond HE into how their experiences as a VI person shaped other life experiences. This reflective process made the research a co-constructed endeavour and centred the importance of participants’ stories and experiences.

Data Analysis

Themes drawn from the interview data created the basis for analysis, highlighting shared commonalities alongside specifically individualised experiences. This resonates with Braun and Clarke’s (2006: 20) suggestion that “data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes”. Analysis emphasised the complex nature of the participants’ experiences and highlighted their unique voices. Ultimately, these experiences reveal the normative expectations and contextual issues regarding HE provision and participation for VI and blind students.

The article now engages with the retellings of participants’ stories related to specific aspects of participation. These are the process of interactions with staff of various kinds, communications between staff and student, and engaging with navigating physical space. Students’ stories begin with reflections on their initial encounters with university support services, move onto issues around communication and space, and end on relationships with support and support workers.

Discussion

Early Involvement

Participants indicate their involvement with support services fluctuated throughout their study, dependent on structural processes and personal circumstances. Participants identified a disconnect between initial engagement with services and eventual university experience. Maddie noted initial meetings, as she embarked on the programme, were suggestive of an environment sensitive to diverse needs, seeking to encourage participation. Organisational restructuring resulted in significant changes during her academic journey:

When I visited the University they impressed me, they gave me their prospectus in Braille. I am a Braille reader, so, that was great! What happened was that I applied, deferred, and when I came back the department had changed. The person that had given me the Braille prospectus no longer worked there and it was no longer the great disability department I had applied for. The lecturers were really surprised when I walked in. I had spoken to the disability department, and they were like, "oh, we couldn't pass on your information because you hadn't signed a consent form".

This lack of communication and loss of an informed member of staff shaped Maddie's studies as necessary support was not in place. The lack of a consent form resulted in access to materials and spaces being unintentionally limited, again influencing how Maddie experienced university. Whilst there is no indication Maddie's needs were deliberately unmet, her experiences may have been more positive, as she suggests, if changes had been better managed.

For Naomi, initial meetings with university support services influenced her decision-making process regarding where to study. Responses and outcomes changed significantly over a comparatively short period of time, resulting in a lack of suitable support.

When we went for my tour of the university, we met the advisor and they were lovely, so helpful, and we thought they are going to understand... They were a nightmare in the end. None of it even happened.

Emily suggested a disconnect between services and a bounded experience of university:

My initial experience of starting at the university was quite disappointing, even though they had been very reassuring and very impressive on the open

days and all the stuff leading up to that. When I got there, very little of the support they had promised me was even put in place.

Impressions of support appear influential as choices are based on a perception of inclusion which can lead to significant outcomes for the individual, such as attending a particular university. These early interactions, whether supportive or disappointing, impacted upon how participants' HE experiences developed. Emily arranged with her HEI early orientation with her new and unfamiliar surroundings by arriving at her halls of residence early. As Emily notes, difficulties with bureaucratic processes prevented her plans:

I was supposed to move into my halls a few days earlier so that I could get orientated with the new place before there were loads of people; they couldn't arrange that mobility for me until November as it was going back and forth between university and Social Services with a lot of blame going on... I couldn't go out on my own, so I had to get my note-takers to meet me and walk me to my lectures and back.

Whilst Emily clearly stipulates that the issues were across two sets of services, the effect on her participation was significant leading to Emily not receiving the support required to begin as an 'independent' HE student. Instead, structural disadvantage meant her participation is bound within others' actions, and the creation of a dependency on other people and services providing resolutions. Crucially, this also changed the dynamic between Emily and those note-takers who are provided to her via the university as support, adding to the inherent conceptualisation of VI. The physical presentation of Emily as requiring guiding embodies the conceptualisation of a VI or blind person as dependent and vulnerable.

What support is provided, and the convoluted, limited, or imprecise language associated with it is indicated in Maddie's reflection on her experience with support staff. Maddie described the support staff she was offered as being note-takers, but the terminology did not represent her needs as a Braille note-taking device user.

I need my note-taker to scribe and to describe visual information to me. They would just find me support workers and say go and take notes for this person, she's blind and I would have to say no, I don't need you to take notes I need you to scribe.

This suggests a generalised labelling and underlying assumption about what is recognised and positioned as support and how it is provided. Additionally in both Emily and Maddie's accounts, the coming together of student and support is managed externally revealing a disconnect between the expectations of student, support worker and organisational input. This is particularly troubling when the experience of being VI or blind is examined through a lens of ableism. Maddie and Emily demonstrate how the role of a support worker or notetaker can be understood through the alternative lenses of those who engage with the process personally and organisationally. This duality, rooted in ableist practices, leads to misunderstandings that highlight the existence of difference as individual and unexpected. This directly places the burden of extra work on the student who is required to solve the imbalance.

Maddie recalls how interactions with support services highlighted a lack of understanding about her requirements and communication preferences.

They would ask me to go in and sign paperwork and I would say "Ok, can you show me where" and they would just say "oh there", and I would tell them that I couldn't see where and they would just say "oh well it's just there".

Maddie, Emily, and Naomi's experiences resonate with Titchkosky (2010: n.p.) who highlights how "[t]he presence and participation of disability "depends" on a host of bureaucratic procedures and is more or less unrelated to people's rights and desire to be present and participate". For all participants the multifarious processes and interactions highlighted the extra work required for them to participate. As Maddie summarises it, her belief is that:

They didn't really know about my needs as a VI person.

Challenging Expectations

Given the dominant neoliberal ideology whereby students are not just attending university to learn, but are purchasing services or products, education is a commodity. However, whether HE is a service or product, universities are marketed as inclusive spaces. Disabled students are granted access based on a tacit understanding that to be part of the system requires a recognition they are different. This understanding also implies they will experience additional processes, and that they should not expect the same consideration or levels of service as non-disabled students. Participants' presence within HE is closely linked to the part played by support services in promoting engagement,

something potentially in tension with their inherent marketing role and, in effect, another version of ableist normativity.

Abrahams, Abbot and Mistry (2020: n.p.) contend ableism can be viewed as an “interpersonal and institutional preference for ‘normal’ bodies and the collective action that sustains exclusionary normalcy”. This can be seen through expectations which pre-exist around VI and blindness, constructions which Michalko (2010: 1) notes as the means with which “blindness comes to us – to blind and sighted people alike – always-already framed by and wrapped in the “one size fits all” conceptual and material clock of culture”. Where expectations are rooted in dis/abling notions, such as a deficit or medicalised understanding, VI and blind students are consistently placed in a homogenising cultural standard drawing heavily on ableist notions of normativity. These initial contacts and eventual actualities indicate that understandings and miscommunication are indicative of the participants’ interactions with the overall institution. Their accounts, in line with Michalko (2010: 1) show how, through the “mirrored shades” of blindness, that “in a world socially organized through and by some version of seeing”, the experience of blindness within HE reflects the social experience of difference present within “culture standard time” (2010: 1). Their accounts indicate how their position has the potential to trouble the “culture standard time” of blindness (Michalko, 2010: 5). As Priestley (1998) contends, collective social values contribute to oppressive behaviours and actions and are manifested through the beliefs and attitudes of others. Participants’ experiences of support services reflect this, as their presence troubles the status quo and is antithetical to the anticipated ideal student construction in HE.

Titchkosky (2000: 197) suggests that examining the discourses of blindness, or disability more generally, shows disabled people positioned as unexpected and unintended people “conditioned by their lack of normalcy in regard to what s/he exerts no control, much of what is done to disabled persons... seems rational and sensible”. This is indicated by Maddie’s account of study.

[the subject] is quite visual and there are a lot of statistics and facts, and the university didn't seem to know how to teach someone that is blind. If they had passed on my information, I think I could have done it but, as it was, they had no clue what to do... I had to drop part in my first year, which meant that I was then a module behind to pass the year. The university paid the cost of me doing the extra module, but it took me four years to do the degree.

As Maddie discusses the consequences associated with the difficulties of participation in a visual subject without adequate support to address the adjustment to a non-visual method of delivery, she again highlights a disconnect between expectation and reality. For Hewett et al. (2017) there is evidence of some providers making reasonable adjustments that enable participation, but what appears apparent is that the dominant social construction held is “eye-sight is the condition of normalcy, the expected, communicative, and yet non-obtrusive fact of normal life.” (Titchkosky 2000: 207). Maddie also describes a lack of communication between departments about requirements of accessibility and barriers that resulted, identifying her disadvantage in comparison to non-disabled peers. This suggests limited value may be placed upon the participation and autonomy of students who require additional means of support, again relating to the construction of the disabled student as a ‘problem’.

To address this may require that the individual continuously emphasises legislative duties of responsibility, given the OfS (2019) report which notes universities are now expected to provide specific types of support as part of their duty of responsibility under the Equality Act (2010). Maddie’s experience indicates that despite legislative impetus regarding reasonable adjustments, underpinning this is a cultural expectation or value associated with visual impairment which contains, constricts, and constrains and is “shared by groups of actors who have a great deal of power over disabled people’s lives” (Priestley 1998: 87).

Engaging with Support Workers

Participants were typically allocated support workers for taught sessions and for individual library or writing provision, but tensions and issues existed within these interactions and relationships. Maddie was unnecessarily provided with support workers/note-takers when what she required was scribing and the description of visual information. This flags up assumptions about what the role entails and who requires this type of support. The expectations of the role on the part of the institution meant the construction of the VI student was homogenised. Maddie’s experience also implies a lack of communication about reasonable adjustments and, consequently, a waste of resources. Maddie’s re-telling highlights the ways in which ableist assumptions surrounding disability and impairment place an expectation on the VI student to manage the relationship. One aspect of support Maddie required was a sighted guide to help her locate a seat, or guide her in unfamiliar locations, such as new classrooms. However, as she outlines, the lack of communication between support services and students resulted in tensions.

They gave me this support worker who was a student herself and she was lovely but shy, so she turned up and said, “oh, I’m here to take notes” and I tried to explain. I said, “could I take your arm, so you could show me to a seat, please” and she wasn’t comfortable at all with it, I could tell. When she guided me, she would bump me into stuff, like completely by accident.

This indicates how for both student and support worker the lack of communication and misunderstanding of requirements meant the relationship was unbalanced, unclear and problematic. Communication, if driven by Maddie’s understanding of her requirements, could have established a productive and autonomous relationship, but this disconnect made it difficult for provision of support in a timely and respectful manner. As support relationships are likely to be complex, generalised training and underpinning assumptions may have negative consequences for VI students. As suggested by the RNIB (2018) when guiding VI and blind people acute awareness is needed of potential hazards. This may seem common sense, but a potential hazard to someone who is sighted is likely to differ from that of a VI or blind person. As in Maddie’s experience the discomfort of the support worker in guiding her became an issue. Had Maddie been able draw on a more autonomous, supported relationship this may have led to an efficient use of resources for the institution as well as making the learning experience more secure.

Communication can be identified as needing to be student-centred and centred on self-advocacy, but there have been contrasting accounts of the latter. Hewett, Douglas and Keil (2016) suggest VI and blind students are often prepared to self-advocate in relation to their support requirements. However, Hewett et al. (2017: 105) note students felt unable to self-advocate in terms of “negotiating support packages; negotiating support arrangements; explaining VI and challenging if things go wrong”. The role of the support worker can also be complicated by organisational policies and expectations rather than individual bias or assumptions (Hannam-Swain: 2018). This suggests that without changes to the current systems, and recognition of the autonomous VI or blind student, these participants in HE will continue be positioned as other, as beneficiaries of adjustments to a space that does not welcome, value, or expect their involvement. This is not to suggest support workers were or are unhelpful or antagonistic, but that the institutional construction of the VI or blind student was either as a problem, or as a rarity where no provision could be planned. Emily recounts how miscommunication resulted in unexpected consequences regarding independence and study as she was allocated a library assistant to help her to navigate her new environment.

I had asked them if I could have another student, I mean they have student reps and student volunteers... I specifically asked them if I could get another student because I didn't want to be the odd one out!

I found later that everyone thought my library assistant was my mum and that was really embarrassing, that people thought my mum was taking me around.

She is a really nice lady, and she was really good at her job but that's not her job either, she's my library support and she shouldn't have to take me round the fair or take me to induction talks and stuff.

This perception of the support worker as parent separated Emily from her student peers. Emily's account shows how she was associated with constructions of disability conflated with dependence, and the disabled person as childlike (Slater 2012), something likely to create barriers to developing peer friendships and shaping HE experiences. Titchkosky's (2000: 207) discussion of the "conspicuousness of blindness" is also relevant here, as it addresses mobility aids that signify blindness, such as a long cane or being guided, as is the case in Emily's account. Titchkosky argues that these aids are made conspicuous as "the lived experience of disability becomes encoded as a series of signs and symptoms in need of deciphering by normative culture" (2000: 218). These signifiers position VI students as 'other', contradicting the conception of an ideal student anticipated within HE and the later ideal citizen (Goodley 2014).

The enforced visibility Emily experienced, as Reeve argues, advantages the "observer with privileged information and therefore power about that body" (2002: 499). Reeve contends that whilst the way disabled people respond to this enforced visibility can vary immensely, it can "leave disabled people feeling ashamed, vulnerable and invalidated" (2002: 499). To be perceived as independent was important for Emily in building relationships with her peers, but the signifiers resulted in a different construction and comparative isolation and initially damaged relations with the support worker:

In a horrible way, I kind of blamed her for a lot in those first few weeks and it kind of put a barrier between our working relationship. I kind of resented her for people thinking that she was my mum, and it wasn't even her fault or mine, it was the institutions' fault for putting us in that situation.

As Emily reflects, her feelings were invalidating of both herself and the support worker, at a time at university when new relationships are tentatively being developed. Reeve (2002: 496) suggests that the first invalidating emotional response is a frequent one and may have developed because of the process

of internalised oppression which, “relies on disabled people internalising the prejudices and stereotypes held by a non-disabled majority”.

Challenging the Expectations

Emily’s experiences serve to illuminate ableist assertions around who is expected to participate in HE. Given the ‘common-sense’ approaches derived from a medicalised view of disability present in HE through implementation and reliance on DSA, alongside cultural notions and expectations about visual impairment, it is perhaps unsurprising support workers figure significantly in the re-telling of lived experiences. Whilst support workers have been identified as an “indispensable support” for VI and blind students (Bishop and Rhind 2011: 186) what this means as a representation of difference is less explored. As Overboe (1999: 25) contends a “normalized embodiment and sensibility”, such as that which arises as a result of an ableist, non-disabled/disabled dichotomy, “sets not only the parameters of ‘what the problem is’, but also the limits of the discussion” and thus non-disabled people preserve and protect their dominant stance. Overboe (1999) further contends disabled people may want to trouble ableist assumptions, such as those shown in Emily’s lived experience, but to do so requires clear lines of communication, and/or the opportunity to present challenges to the subordinate position imposed upon disabled people. There are many similar situations where disabled people need to consider whether they can, do, or do not present challenges to the ableist discourses underpinning disabled people’s lives.

William also notes a perceived barrier between he and his peers because of imposed visibility as other:

I had a sighted guide/note-taker. I got introduced to her before beginning my course. I didn’t really get introduced to anyone else on my course. I ended up just hanging around with her for the whole three years, increasingly more and more through the three years, I would be with people I had started speaking to on my course, but it was mainly the note-taker. We had similar interests in films and music and stuff, we became good friends to be honest...

I think more and more people just expected that she and I were friends and that became a way to not be able to make more friends. In a way it didn’t matter but I felt like they wouldn’t, or felt they couldn’t, intrude. It would have been nice to have more friends, like the guys on the course, a bit more.

William can be positioned through the gaze of the “normate”, a cultural construction whereby non-disabled people, as noted above, are regarded as

“definitive human beings” (Thomson 1997: 8). This is a subject position whereby non-disabled people are “generally intended and expected by the normal order of interaction, the physical environment and the structures of knowledge production” and by which this “ideological code” and “normate culture” seeks to “exclude, oppress and remove definitional power” (Titchkosky 2000: 214). The visual reminder, through the support worker, of a construction of difference conceptualises and re-conceptualises William as different.

Luke and Martin’s accounts indicate being male mature students had an impact on experience of university and support relationships different to that of younger participants. They recognised the importance of support workers but were confident in insisting this role could take a form suitable to their specific needs. Both felt their age made them more comfortable about self-advocacy. Martin said:

I don't have a support worker; I meet a guy off my course at the train station and he walks along with me. The rooms don't change much with us being part time and everything I need in terms of access to journals and books is online, so, simple. So, I don't need a support worker.

Similarly, Luke was very clear regarding what support he did or did not require.

I used most of my DSA to get someone to scan books for me, 'cos that would have taken so much time... when I go back now, this time, because I have been doing things for so long it was easy to tell them what I need, additional time if needed for submission and additional support for library.

Both were conscious that age, gender and working roles gave them confidence in organising support. Both have professional roles working with VI or blind people, perhaps ensuring knowledge and authority when dealing with support services. That their experiences differ to those of the younger research participants suggests an intersection of factors, such as gender, age, and professional knowledge impacts upon support in HE. Hewett et al’s (2017) study into the experiences of VI and blind students highlighted that support staff and disability services staff had expectations that learners should ‘self-advocate’ regarding requirements, and they concluded there was “a lack of specialist knowledge of how to make accommodations for students with VI” (2017: 104). This suggests where support and disability services are positioned as expert and given the power to demarcate what VI and blind students receive, there appear likely to be issues around access to HE. The rhetoric of self-advocacy could be seen as handing responsibility to the student and potentially both

negative and positive. As these accounts suggest this may exacerbate power imbalances rather than correct them.

A final account of relationships with support workers came from Georgia. She notes how the relationship with her support worker was crucial to her participation within academic life, yet it simultaneously created barriers. She summarises key points mentioned above, stating,

I think it can be quite difficult if you are sat with a support worker, it can make it quite difficult for people to approach you and for you to approach other people particularly if you have a visual impairment.

In my experience it is harder to judge that situation, particularly meeting people. It is more difficult than it would be normally, and I think in a uni situation when you are new, everyone is a little awkward and it is all a little bit strange and difficult. I think it does make it a bit more difficult but at the same time if you went in and didn't have that support you would be even more nervous about it.

I would have been more nervous going into classes with nobody I knew and having to meet people. At least you have that person there to help you and be like “oh, this person is talking to you”.

Georgia's reflections reveal the intersections between being perceived as already having a companion, their role as facilitator, and visual impairment.

Conclusion

Participants accounts showed that complex relationships with support workers influenced their experience of HE whilst acknowledging, in most instances, the positive rapport with various support workers. Barriers existed because of negative connotations held by others, and sometimes internalised, with having a support worker. This was compounded if a support worker adopted a peer role, resulting in comparative isolation from a wider network of potential friendships. There appears a trade-off between being fully included in a peer group and relying on a support worker for aspects of study. There also appear to be issues relating to the management of this relationship, particularly when students experience underlying assumptions about being VI or blind.

This article indicates the self-perception of the participants, their internalisation of wider understandings of them by others, and their fears and concerns about what others may think, is impactful. In effect, assumptions on the part of services, and their subsequent actions, can undermine VI students' sense

of self and confidence in relation to their peers. Finally, the use of support workers, recognised as crucial to the participation of v1 students, can be perceived as more related to support services than students. The service can take precedence over the individual relating to an expectation that what v1 or blind students require should be delineated by support services; an ableist and normative assumption. Decisions are typically made without including the student unless they are prepared to challenge and self-advocate, which this group confirm as potentially problematic and challenging.

Their participation is decided in terms of the structural and societal expectations of the anticipation of what v1 or blind people do and what is allowed and decided in terms of dominant discourses, social constructions and existing and developing power relationships. This suggests participation is dependent on the space rendered appropriate, engagement with constructions associated with a disabled identity and a constant and fluctuating negotiation and renegotiation of inclusion and participation. This highlights the ongoing requirement for structural change which takes a stance against disabling and negative constructions associated with being v1 or blind and which actively welcomes and supports the position of the individual as expert in their own lives.

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