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# **Constructions and Paradigms in Tension: Visually Impaired Students and Higher Education**

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**Northumbria  
University**  
NEWCASTLE

# **Constructions and Paradigms in Tension: Visually Impaired Students and Higher Education**

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## **Abstract**

Whilst there has been research that has examined the experiences of disabled students in higher education, to date none has examined the experience of being visually impaired -and- being a visually impaired student. By utilising a Critical Disability Studies (CDS) approach I consider how visually impaired students experience non-normative and ableist discourses within their life as a student as well as in their day to day lives beyond university. In doing so I show that for visually impaired students, higher education is a complex arena where there are allusions to participation and transformation, yet the sector often reinforces oppressive and disabling notions. The disabling attitudes and actions, regarding visual impairment, these students experience are culturally and historically rooted in concepts heavily loaded with tragedy, pity and fear.

Using a critical Grounded Theory approach (Charmaz, 2014) I examine the experiences of a sample of participants drawn from an informal network and as told within loose semi structured interviews in which participants talked about their experiences as a student and their experiences as a visually impaired person, more generally, contextualising their university experience within it. Participants' accounts highlight the complex systems within education that they are required to negotiate as a disabled student and, critically, they emphasise the many and complex interactions experienced in their daily lives. At the intersections of these two sets of experiences are often ableist assertions about visual impairment and visually impaired people, and the interviews show the importance of questioning normative discourses about visual impairment. I argue that despite many attempts to challenge disabling discourses these remain prevalent in contemporary HE and that taking an intersectional, CDS approach can reconceptualise being a visually impaired student as an autonomous and non-tragic identity, which in turn promotes a participatory and transformative higher education experience.

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## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee / University Ethics Committee on 02/03/2016

**I declare that the Word Count of this Thesis is 84,590 words**

Name: Emma Louise Croft

Signature: E Croft

Date: Sept 2018



## **Introduction**

This thesis presents an exploration of blind and visually impaired (VI) students' interpretations of their experiences in higher education (HE) in the United Kingdom. These experiences illustrate a central issue, the core of the thesis, in which two very different paradigms, those of HE in general and of their specific higher education institutions (HEIs), and those of blindness and visual impairment, are in tension in various ways. These might be seen as productive tensions, on the one hand, but on the other they may be seen as clashing and, consequently, have a negative impact upon the actual HE experiences of visually impaired students. That these students are aware of these different paradigms is suggested by their accounts, as I discuss later. Further, there may also be a tension between the position of the blind or visually impaired student as disabled citizen with rights and as subject of an educational system, if it is one in which an ableist construction of the student is dominant. In addition, the accounts suggest that within HE there may be a range of differing perspectives or constructions regarding blindness and visual impairment according to service or department, as well as the overarching policy statements of any given institution. The juxtaposition of these different paradigms may be positive yet might also be potentially be seen as resulting in a fundamental disjuncture, as will be explored.

Whilst there is previous research in related areas, predominantly on the wider experience of disability in HE, it does not address or examine this specific area in any depth. In addition, existing research tends to exist in a vacuum in that it is only the actual experience of study that is explored, not the broader context of being a visually impaired person at university and the relationship between that and wider educational autobiographies. Discussion of the existing research in the literature review highlights the gaps in the existing knowledge base.

In contrast, in this research the actual experiences of individuals are juxtaposed with how being a person who is blind or visually impaired is constructed within HE and wider society. This thesis demonstrates that in order to understand what being a blind or visually impaired student means, it is necessary to engage with the wider implications of being blind or visually impaired, thus explicitly rejecting the notion of considering only a single aspect of lived experience.

Firstly, I turn to discuss the language of visual impairment and blindness and its use throughout this thesis. Within the United Kingdom, where this research has been carried out, terminology around blindness and visual impairment often appears to be used interchangeably and often depends on the overarching intention behind use. Frequently, visual impairment or blindness is discussed in terms of being sight impaired or severely sight impaired. For example, and as discussed later in this thesis in relation to the policy drivers which influence how visual impairment and blindness are constructed, how a person is defined requires assessment by registered ophthalmologists (Department of Health, 2013) which correlates to a labelling of sight impaired or severely sight impaired. Rather than draw upon medicalised terminology where language can position impairment and the impaired person as deficient and lacking, I engage with more common usages that are employed by visually impaired people themselves across the findings of this research. However, I recognise that how visual impairment and blindness as signifiers of a sight impairment are used across different contexts and countries can vary significantly. I thus suggest that within this thesis, in order to address this and provide a fluid reading and continuity, I engage the term visually impaired to address the multitude of understandings and as a means to tackle the tricky subject of language and to avoid connotations of loss and deficit. Where participants later employ terms such as blindness, I engage these as personal

descriptors and encourage examination of personal reflections as the expert position around their own lives and the ways in which they choose to identify their experiences. I recognise the interchangeability of the terminology and encourage examination of this across the reading of this thesis as an early introduction to the intricacies of people's lives.

This means that this thesis employs a theoretical lens that enables analysis of several aspects of each research participant's life. To this purpose, I work particularly with a critical disability studies (CDS) approach, employing the tools offered by this theoretical position. I also draw on other models regarding disability in establishing the background to this study and in the literature review. In addition, my epistemological perspective is social constructionist, as discussed later in the methodology chapter. I feel that to explore this topic necessitates a commitment to exploring and conceptualising the intersections of being 'visually impaired', 'a student', 'disabled' and 'a visually impaired student'. I look at these elements and, in considering the intersections, examine how these identities might come together or exist in tension. CDS is especially suited to this research, for, as the identities outlined above suggest, this thesis needs to take a cross and inter-disciplinary approach and CDS draws upon critical theories from a range of disciplines and positions (Goodley, 2014). Further, as discussed within the methodology chapter, I engage with a critical Grounded Theory approach (Charmaz, 2014) in relation to the collection and thematic analysis (Braun and Clarke, 2006) of participants' educational life experiences.

I address here also the terms laid out in the title of this thesis in order to provide definition to their inclusion. I engage with the term paradigm as a way to discuss the associations attached to the experience of being visually impaired, typically discussed within wider general disability studies material and literature and

about disability broadly and more narrowly. I suggest that the paradigm as it relates to this topic is that disability is inextricably linked to negative connotations of deficit, difference and lack of value. In that sense where I call out a tension is where this thesis shows that for visually impaired people themselves their lives often do not fit in this pattern of negativity and associated difference and instead their lives conflict with the overarching associations linked with being visually impaired. As I discuss and as we uncover throughout this thesis the experience of being visually impaired is one which is often enforced with negativity and the tension arises from the friction this causes where visually impaired people are unwilling to be positioned within these negative connotations and offer up insightful and challenging ways to manoeuvre these assumptions. Finally, where I draw upon constructions I do so from a social constructionist standpoint which recognises the myriad of ways in which experiences and narratives build these assumptions around disability and this construct understanding.

I begin this thesis by exploring my own positionality in terms of insider/outsider perspectives regarding the VI community and my thinking about it. I am not a visually impaired person but will indicate how my involvement in a VI community, alongside visually impaired people who are part of my life, gave me the initial motivation to begin this research and has contributed to my understanding of the specific lived experience of this group of students.

Thus, the following section discusses in more depth the personal experiences that have led to the development of this research. I begin by tracing a path through these experiences, my professional life, and academic career, to indicate the influence of each upon my current position. I additionally show how and what thinking cements my positionality as a researcher in this field. I continue by

discussing the philosophical and personal factors that underpin the research. In doing so I further highlight the conceptual lens that is applied throughout the thesis.

I follow this by mapping out the conceptual framework that underpins the thesis (Miles and Huberman, 1994, p.18). In terms of this research, I envisage the conceptual framework as a series of circles, interlinking and forming a wider circle around the experience of being visually impaired. For me, this highlights the ways in which being a visually impaired student can be constructed in terms of the factors at play within individual and collective experience.

Finally, I examine the ways in which disability and visual impairment are constructed through existing and emergent cultural, societal, organisational and individual interpretations. Through a critical evaluation of these constructions I will show how they inform the current landscape that these students move within. This is the basis for the exploration of the lived experience of visually impaired students and the ways in which abstract constructions of the student and HE also impact upon them.

### **Making the personal, political**

Embarking on the path to this research began by chance. After completing my undergraduate degree, I worked with a local charity that supported and engaged with visually impaired people. I became keen to investigate some aspects of my professional role through the lenses I had developed an interest in during my studies. Part of my role involved working with visually impaired students preparing to apply for further education (FE) or HE. These prospective students seemed in more emotional and intellectual turmoil regarding the expectations placed upon them regarding studying at these levels than other students I had met. They were also more concerned about where they would study and what support they might

receive. I became very conscious that they felt unable to get their views across about what they needed in terms of support and personal development in order to access their chosen studies. Simultaneously, I became frustrated with the way that, whilst experiencing turmoil, they also expressed an acceptance of their position as unlikely to receive appropriate treatment, stating that that was just 'how it was'. This complex emotional state, which combined passivity and fatalism, tentative aspiration and assertion, suggested that both educational sectors needed to make an offer to students that was clear enough to reduce their fears. This implied, in turn, that these educational sectors required more understanding of visually impaired students and their needs, and more understanding of their own constructions of the VI student.

Working with these potential students was informative, both in terms of how they came to negotiate FE and HE, but also in suggesting that more research was needed in this area. I consequently embarked on study at master's level, which enabled me to begin investigating the experiences of visually impaired students in HE. The discourses that emerged from this research led me to engage with several philosophical questions about the discussions surrounding disability, impairment and visual impairment. I came to question the prevailing discourses presented as the common-sense approaches to working with disability and specifically, visual impairment, through a consistent and overt narrative which positioned 'living with sight loss', as the ultimate triumph. This triumph seemed to be couched in terms of only being achievable by acting like a non-visually impaired person, managing tasks as they would and 'passing' as sighted. Contrastingly, not achieving this benchmark brought with it an assumption of weakness and/or deviance, suggesting that common-sense notions are inherently problematic.

Much of the professional work I was involved in, which ran concurrently with my studies, appeared to engage an underlying discourse which conceptualised disability as an individual pathology; problematised disability as requiring treatment, or as a personal tragedy and thus to be pitied (Danieli & Woodhams, 2005). In my professional role, I supported and encouraged colleagues, students, institutions and the VI community in challenging what people presumed was 'normal' for a visually impaired person. In considering my experiences, I began to question the extent to which the experiences of visually impaired students were included in the literature and rhetoric around disability and education and whether research, practice and understanding around participation could engage with contemporary social discourses and constructions of disability.

My personal experience of the discourses about, and barriers presented to, people with visual impairment has also informed my research focus and I draw upon Dan Goodley's explanation of the ways in which drawing out such experiences can help to illuminate that which is being examined. He states that "politicising the personal exposes the ways in which our interiorities – our physiological, neurological and physical lives - are felt through the social, cultural, political and economic" (Goodley, 2014, p.48). My partner is registered severely sight impaired (SSI) and is a guide dog user. In our family life, we experience a broad spectrum of attitudes and expectations related to visual impairment and disability in seemingly innocuous everyday situations. I outline some of the experiences that occur to help to convey my own positionality about the research and in doing so show its possible importance in exploring assumptions typically made about the lives of visually impaired people, whether studying at university or otherwise.

These experiences are very varied and range from assumptions about requirements to physical and environmental barriers. For example, in a restaurant it

may be assumed that a Braille menu is required. Additional barriers in this setting may include being seated in a dark corner as we as a family have a guide dog with us. There are also issues around communication. My partner is frequently ignored, and verbal communications are typically addressed to me. A more specific example is that many firms and individuals seem unable to provide written communications in an email format which would enable my partner to engage directly with information rather than rely on others to read out letters.

Further, ordinary daily experiences include having to explain to others, or being explained to others. For example, there are regularly loud comments pointing my partner out, including ones along the lines of ‘the special dog, with the special eyes for the special man’. Similar incidents involve the schoolyard conversations that my young daughter has with her peers explaining why we as a family have a guide dog with us. Additionally, there are sometimes conversations with parents who are worried or anxious that their child’s attempts at interaction with the guide dog is a distraction for the dog, and who express surprise when we actively engage in conversations about visual impairment and the dog’s purpose. These interactions are not intended to be microaggressions, yet all the same, these conversations and observations constantly do ‘other’ my partner and our family, demanding explanations and justifications. This is in line with Wing Sue’s (2010, p.245) definition of microaggressions as “insults and invalidations” which “make their appearance in interpersonal and environmental encounters”. This process of othering is part of the intersectional underpinnings of experience for those who are marginalised and experience life on the fringes of participation. As Goodley argues:

Disabled people, women, children, queer people, people of colour and poor people share an Other space to that of the dominant same founded upon ableist, heteronormative, adult, white European and North American, high income nations’ values. (Goodley, 2014, pp.22-23).



Thus, whilst it could be argued that there is no overtly negative foundation to such interactions and assertions, they do serve to accentuate difference and privilege.

These interactions also relate to the notion of the other as uncanny, of being beyond what is normal or expected, as liminal. As Goodley (2014, p.119) further argues,

Because disability includes the hidden yet present referent of ability it should come as no surprise to argue that dis/ability is an uncanny thing. After all, it exists as an apex between binaries such as in/competent, strange/familiar and ab/normality. Reactions range from hatred, to benign curiosity, to desire.

In our everyday life Goodley's comment is very apposite. My partner is an active guest speaker who visits schools, community groups and other organisations to talk about his experience of visual impairment; attempting to promote a better understanding of visual impairment and more widely, disability. In these situations, he is constructed as an expert and as an invited speaker, both of which confer authority. Yet whilst these interactions may appear seemingly positive, they remain linked to explaining oneself for the benefit of others. At the very least, these talks can be seen as a reflection of the reaction of "benign curiosity" (ibid.) and act as an attempt to explore the spaces between the binaries that Goodley highlights, on the part of the schools and other organisations. In other respects, however, these situations can serve to meet the limited expectations of those who invite him to talk to their groups.

Fascination about visual impairment and the ways in which this presents itself in terms of involvement within wider society can often be a motivator for non-visually impaired individuals to initiate such interactions, something which could also and could be construed as oppressive. Participation in terms of ensuring that basic awareness training within organisations, for example, harks towards a tokenistic garnering of understanding and as such reinforces negativity and othering towards

visually impaired people. My experience of delivering basic visual awareness training taught me that sighted people can be enthralled by visual impairment and the necessary adjustments and equipment that visually impaired people use every day. Whilst such awareness raising is vital in order to challenge assumptions and inherent beliefs about visual impairment, there often remains a morbid attraction in simulating blindness within such sessions in order to temporarily experience it. Having delivered training, I am aware of the tensions within it and, further, of having to engage with tensions around my roles as partner and trainer.

Furthermore, as Titchkosky (2003, p.75) states, there is present within interactions between visually impaired people and those without impairment, a “double bind... ubiquitously enforced by those who have sight... upon those who do not”. She discusses this double bind through her experiences of life with her partner. In doing so Titchkosky reflects upon the ways in which she navigates the space between sighted and non-sighted, a unique subject position explored throughout her work. She, as a sighted person, is required to act, to ‘become’, blind in the same ways in which, she observes, her partner experiences the need to act like and pass for a sighted person. She discusses how the retelling of stories and experiences of her partner would raise enjoyment and pleasure for others as the peculiarities of the sighted and non/sighted interactions were shared amongst peers and friends, something which calls upon her partner to “act as a normal sighted person, while you tell us all about the abnormalcy of blindness” (Titchkosky, 2003, p.75). For Titchkosky this double bind is prevalent in interactions where visual impairment is moved from being an embodied experience to an abstract, an ‘out there’ and thus separate concept, open for discussion. Similarly, the ways in which ‘being blind’ is experienced as a site for fascination and curiosity through experiencing visual

impairment through, for instance, awareness raising sessions, as noted earlier, she suggests leads to blindness being considered in particular, distanced ways:

...as an object for conversation, but do not give us blindness as a subjective state of affairs which reorganizes and influences our normal means of engagement. The double bind is grounded in an implicit imperative: say what you will but do as we do... the imperative represents another way to make disability thing-like in that it involves offering blindness up as an object for discussion whilst obliterating any subjective interactional consciousness of blindness.

(Titchkosky, 2003, p.75)

Titchkosky argues that the experience of being visually impaired or blind cannot be understood solely by simulating blindness through the wearing of glasses or a blindfold, although this is a common approach in training. Instead, Titchkosky (2003) contends,

Blindness as an interactional event, out there, can be charted. But it is like looking at a map of foreign land which no one has any intention of visiting. The map can be interesting but remains inconsequential for those who gaze upon it. It is not, of course, inconsequential for the life of the person so mapped

(Titchkosky, 2003, p.75).

This double bind and removal from embodiment is similar to that which 'others' a range of marginalised groups, such as those discussed, above, by Goodley.

Engaging with Titchkosky's empathetic discussion about the life she shares with her partner is relevant to my examination of my life with my partner. I share the experience of being expected to act a certain way when I am out with my partner and from a personal perspective it becomes frustrating and is experienced as oppressive. However, in terms of constructing interview schedules, building empathy and analysing the data contributed by the research participants, my experiences were very useful. They not only gave us a common ground but created a level of openness that may have been difficult to achieve otherwise, adding

uniqueness to the research. When my partner and I began our relationship, I swiftly realised the level of cultural expectation that is placed on the idea of being in what is constructed as a 'normal' relationship according to dominant discourses, one where both parties are assumed to contribute to the financial necessities of family life, sharing childcare, housework and all the other things that families supposedly do. Whilst that had never seemed important to me, even as an aspiration, I became more aware that people had very definite expectations about what being part of a 'disabled' couple and 'disabled' family meant and what that entailed, or perhaps more to the point, what it did not.

When embarking on this research and exploring what it was about it that made me 'tick', I realised that my engagement hinged on how uncomfortable I was with the connotations that were associated with visual impairment and the impact this has upon individuals and families. I initially considered avoiding including my own experiences, given my detachment from the immediate aspects of VI, in an attempt to 'take myself out' of the research process, but sharply realised that that made me feel fraudulent and uneasy. I was in this research whether I liked it or not, something I discuss further below.

Overall, other people's assertions about visual impairment and blindness are a dominant discourse in my family's lives. The personal recognition of this point informs this research. The interviews that are central to this thesis indicate that these also form part of a central discourse pervading the lives of all those who took part in the research and construct them in very specific ways. Of interest is one common refrain, the phrase 'You don't look blind'. This term can be read in several ways. On the one hand it inherently questions those it is addressed to, suggesting that they are somehow fraudulent. On the other, those offering it, given the discourse that privileges passing as sighted, may consider it a compliment. In both cases, however,

the comment is 'othering'. Further, it reveals both a stereotypical image of blindness and suggests that non-conformity might subvert this, but also that a non-stereotypical performance may also result in an increased occurrence of microaggressions.

Finally, and linking back with my professional role, specified training tasks like simulating blindness, whilst potentially encouraging a positive understanding of visual impairment, are contained within a limited temporal space. Consequently, the experience and understanding of participants regarding meeting anyone who is visually impaired beyond the space and context of that task will still be heavily drawn from participants' prior expectations about who can be blind and how they can act or appear, so having little impact upon 'othering' practices.

### **My positionality within this thesis**

Due to the personal and professional experiences I bring to this research, talking through my positionality as a researcher is important. As a non-disabled researcher, I can make no claims towards being or understanding what it is to live as a visually impaired person. However, as Titchkosky states, "a 'disabled identity' does not belong strictly and only to those of us who are identified as disabled" (2003, p.4). In this research, then, as well as drawing upon academic and first-person accounts, particularly the work of Michalko and Titchkosky, I also draw on my first-hand experience of VI communities both professional and personal. This combination helps me elucidate where I envisage my position to be.

One particularly helpful concept is offered by Michalko (1999, pp.8-9) when he discusses how, with his guide dog, Smokie, their journey through the world is one that is carried out in what he calls "the alone-together". This concept helps me understand the multifaceted roles and experiences explored throughout this thesis

in terms of my own positionality as well as that of the HE students I interviewed. The concept of “alone-together”, Michalko suggests, relates to the ways in which the two of them experience being blind as they negotiate the world. Here the intersections of human/animal or societal/natural life and the constructions associated with them link with the roles and constructions played out within this thesis.

As noted in the previous section, my position within this research is both complex and yet very simple. As I began work on this study, I was a novice researcher, yet had a great amount of experience working and being with visually impaired people. Within my friendship group and the people that I worked with, I spent a great amount of time travelling to and from venues and events, guiding and being guided (when my inevitable lack of direction took over), ‘hanging out with’ and teaching visually impaired and blind people. It was, and still is, central to my day to day life. Using Michalko’s concept, I became aware that I serve as an intersection point between a number of constructions – researcher, support worker, partner, friend and sighted guide.

In addition, referring back to Titchkosky’s exploration of her experiences of being dyslexic and of living with blindness, she argues that to understand the wider societal conceptions of disability there should be a ‘re-appropriation’ of disability, “taking back, talking back, and staying with the experience so as to reveal the meaning that has already been granted to disability by culture, by others and by me” (Titchkosky, 2003, p.5). This re-appropriation enables me to peel back layers, to understand the meanings of disability in a lived context and to examine intersections.

An aspect of one of these layers is analysed by Michalko (1999) in his exploration of the notion of togetherness. He argues that his partnership with Smokie takes them on a trajectory whereby conceptions of their togetherness are

always present. They thus experience the constructions people hold about what visual impairment and blindness are, and how and where and within whom these are embodied. In addition, he argues that through experiencing togetherness and the connotations attached to it of who or what blindness is and can be he feels they are culturally constant. This idea of cultural constancy re-emerges in my later discussion of student experience. In my own case, his arguments accompany me as I walk metaphorically and figuratively with my partner, my friends, and my participants. Michalko (1999, p.8) notes about his own perception of how people observe him and his guide dog:

Smokie and I are not anonymous travellers in our world. Everyone notices us. And when they do, they see certain things about us. When people notice Smokie and me they see us through their particular construction of blindness.

This latter concept about constructions of blindness is a key aspect of this research.

What Michalko's account suggests is that the understanding and experience of visual impairment is constructed by multiple sources. In my case these are; professional experiences, academic work, personal life, the stories told to me, those that I am creating with others, and those being shared by friends or participants, the media and society. These sources are added to by the passing looks at my companion and those at me, the dog, the children. We are thus contained and constrained within other people's understanding and beliefs about what it is to be visually impaired or blind, and those of the people and spaces that visual impairment and blindness exists within and alongside. Furthermore, these assumptions construct a wider narrative about who we are and how we navigate the spaces we inhabit. Alone-together and togetherness, then, can be argued to encompass our experiences.

## **Key Theoretical Areas Influencing the Research: Models, Bodies and Minds.**

There are several theoretical influences upon this research. I turn first to the Social Model of disability perspective, outlining how it is illuminating regarding the experience of visual impairment, but also suggesting potential limitations. Oliver (1990) in his seminal work *The Politics of Disablement* discusses the development of the Social Model of disability as emerging in response to the medicalised view, one which had dominated, and perhaps still does dominate, social interactions and social policy.

Developing from disability activism, the Union of the Physically Impaired Against Segregation (UPIAS) (1976) established an alternative structure with which to construct impairment and disability:

Impairment: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities.

These definitions were later expanded to include sensory, emotional and cognitive impairment (Barnes, 1994). This position understands disability, as summarised by Michalko (2002), as the happenings and experiences which force constraints upon disabled people, from inaccessible buildings to unsuitable policy, transport systems which disabled people are unable to access and segregated education and limited employment opportunities.

Visual impairment when examined through this perspective is identified as an impairment in visual function. However, it is also, like all perceived disability, recognised, as Oliver (1990) states, as the disadvantages and restrictions



experienced as a result of an oppressive society through inaccessible, exclusionary and inappropriate physical or attitudinal barriers.

Visually impaired people are thus defined in terms of what Barnes (1998, p.78) states are their “biological characteristics” and the “inability of society to address the needs of disabled people”. Further, Michalko (2002) notes that the social model accepts:

The biological fact of disability ... reframing it as impairment... thus the disabling conditions “suffered” by disabled people are not those imposed on us by our biological conditions but instead are interpretations and images of our impairments imposed on us by society.

In comparison to a medical model of disability, which positioned impairment as the biological condition of a non-normal body and a “medical hegemony of ... rehabilitation and education” (Michalko, 2002, p.53), Cameron (2014) contended that the Social Model created an understanding that what disabled people needed was political action as opposed to therapeutic intervention. He argued that legally enshrined changes needed to be made that alter access, change policy responses and develop a new discourse about disability. Constructing impairment and disability in this way moves the focus away from the deficit experienced by the individual because of their impairment, shifts the discourse of impairment away from negative individualised language, and instead collectivises experience to develop a politicised claim for equality.

The Social Model has thus been recognised as a tool to provide disabled people with a robust foundation in which to ground their claims for equality (Cameron, 2014) and, arguably, has been turned into practice by organisations and practices. Yet without fully understanding what it means and adopting the terminology as a coverall phrase or action, it becomes a ‘sticking plaster’ statement

highlighting that an organisation or society are accepting of and seeking promotion of disabled people's rights. Indeed, as Oliver (2004) notes, the Social Model has little influence on professional practice and was not meant to answer all questions about disability, was not posited as a grand theory of disability, and was ultimately suggested as a collective answer to the experience of oppressive practices imposed upon disabled people (Oliver, 2009). In other words, it can be used to explain what 'goes on' rather than why it 'goes on'.

As a consequence of such realisations, the Social Model has been heavily criticised. Corker and French (1999), for instance, note that it rejects personal experiences of living with impairment and Crow (1996) similarly argues that it ignores the lived experiences of individuals, stating that she sees collectivising disabled people as generalizing and homogenizing rather than politicising.

This model aims to tackle exclusionary barriers, yet the positioning of disability as something outside the body and thus separate to impairment, as Hughes and Paterson (1997) suggest, means that "the Social Model – in spite of its critique of the medical model - actually concedes the body to medicine and understands impairment in terms of medical discourse" (1997, p.326). Thus, this separation of disability and impairment de-medicalises disability "but simultaneously leaves the impaired body in the exclusive jurisdiction of medical hermeneutics" (Hughes and Paterson, 1997, p.152).

This distinction is apparent regarding visual impairment. Visual impairment is the domain of a medicalised understanding of sight as impaired and thus people with impaired sight as visually impaired people or as having a visual impairment. This subject position is a negative one yet is necessary to understand it to understand the barriers that impact upon participation and therefore be able to raise any challenge to them. Identifying the barriers gives credence to the difference that

is inherent due to a definition of visual impairment that is rooted in a medicalised discourse.

This means that in terms of my examination of the HE experiences of visually impaired people; the Social Model offers a useful insight into the way impairment and disability are constructed within society. The prevalence of this model to explain the barriers that disabled people experience has been crucial to the development of challenges to medicalised discourses that root disability as the fault of the individual. Additionally, I acknowledge that the political challenge it has brought to the experience of being disabled is hugely significant, politicising disability as a distinct category, thereby adding much to what is known about the lives of disabled people, as well as how this changes approaches to disabling societal conditions especially economic, financial and social barriers.

However, despite its usefulness, it is limited in how much it can illuminate the focus of this project, the experiences of visually impaired people in HE and the potential tensions between HE and VI. Whilst I am entirely in agreement that the experience of being VI can be understood in terms of the Social Model definitions, I would argue that this does not allow effective exploration of the complexity of individual experiences in relation to the multiple structures within HEIs and therefore any discussions of visual impairment and higher education do not end with disability.

Developed in response to the medical or individual model of disability (Oliver, 1990), and as a challenge arising from the disability activism of that time, the Social Model positions the impact of impairment in a collective way, not as an individual issue. This collectivisation of the experience of disability has, as noted, had an impact upon constraints on the lives of disabled people, becoming the 'way of thinking' about disability and a marker of good practice. However, this generalised tool cannot adequately account for individual experience of needs, as the analysis

of the interviews later suggest. Further, whilst it helps to challenge the economic, cultural and social barriers disabled people face to participation in equal terms to that of non-disabled people, a concept Goodley describes as factors of disablement (Goodley, 2014, p.7), it creates a dichotomy of disabled and non-disabled within HE that is problematic. In conclusion, the positioning of the Social Model to examine the material conditions in which disablism exists disregards experiences within the body, and as such is only partly useful this research.

As an addition to the Social Model, the Affirmation Model was originally developed by Swain and French (2000, p.150) and proposed as:

A non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people, grounded in the benefits of a lifestyle and life experiences of being impaired and disabled.

This model offers an alternative viewpoint through which to examine visual impairment. Working with and adapting the UPIAS (1976) definitions, Cameron (2014, p.6) proposed the following affirmation model:

Impairment: physical, sensory, emotional and cognitive difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

Disability: a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal.

This discourse suggests that disability is a role which is imposed upon individuals. It positions society as disabling, discriminatory and oppressive. The definitions it offers allow visually impaired people to locate their impairment within sensory difference. Instead of visual impairment being heavily imbued with negative connotations of loss and limitation, employing this model means that it can be argued that it should be recognised as valued and accepted positively. This model,

however, as is emphatically argued by Swain and French (2000) is not about positioning disabled people as “coming to terms with’ disability and impairment” or as “can do’ or ‘lovely’ people” or as discussing “the benefits of living and being marginalised and segregated within a disablist society” (p.185).

It is here that the Affirmation Model provides an interesting alternative construction. Here, visually impaired people are not considered to be disabled by their impairment. Visual impairment, from this perspective, is to be expected and respected due to the diversity of societies and the likelihood that impairment will exist in many guises. The role of societal understandings of disability are altered to ones where being disabled is a role that is played out and which takes into consideration the power dynamics at play in traditional definitions of disability. Disability remains oppressive, through the implementation of this power dynamic; however, visually impaired people can engage with their experiences through a stronger fundamental position that recognises the value of impairment and diversity.

In terms of positioning the Affirmation Model to address issues of impairment and disability, the definitions Cameron (2014) proposed offer a useful lens through which to view what happens in disabling encounters and to understand the roles that disabled people and non-disabled people play. Cameron (2014, p.6) contends that the Affirmation Model is “a resource to be used by disabled people in refusing to be what we are expected to become” and when engaged with as a tool by disabled people to help understanding and develop challenges, it could help construct a rebuttal of negative expectations and experiences and help make sense of these in terms of a power dichotomy between non-disabled and disabled persons.

However, despite the usefulness of Cameron’s development of the affirmation model as a resource for disabled people based in the experience of being disabled, there are limitations regarding the applicability of this model to explain the

experiences of visually impaired students. This recently developed model supports a strong politicisation of the experience of being disabled, but it is difficult to envisage how it can encourage mobilisation against the imposition of the role of being disabled or help individuals question how they are constructed within society.

In addition, the criticisms of the Social model regarding its lack of an intersectional approach can also be applied to the Affirmation model. The former began a slow and partial change, yet it has still not resulted in the removal of barriers or the oppression that disabled people face. This is indicated by the continuing way that impairment is perceived as different from the norms that are culturally valued – healthy/non-disabled/non-impaired bodies.

As with the former model, the Affirmation model offers up a way to understand that impairment and disabling barriers are at play, yet by the attempt to remove the barriers associated with disability this negates the importance of the body as a site of discussion, or of how multiple factors might be at play in addition to disability, such as class, ethnicity, gender or age. Further, as Crow (1996, p.209) contends, when impairment is recognised as pain or chronic illness, the removal of disabling barriers will not remove the pain, or the discomfort impairment may cause. Arguably, neither model exists to engage with, for instance, racism or sexism, but this again means that complex individual experience tends to be subsumed, whilst I intend to explore precisely that.

In exploring the importance of the body and the physical, I turn to another set of key ideas. In her influential *Female Forms: Experiencing and Understanding Disability* Thomas (1999, p.155) argued for a different analysis of disability, one which incorporates the “location of experience in its broader sociological context”, taking on board, rather than rejecting, a dualism that will “bridge agency and

structure”. In this Thomas argues that it is the interaction between disability and impairment, acted out in a social setting, which causes oppression.

Thomas (1999, p.43) discusses the effects of impairments referring to the “restrictions of activity which are associated with being impaired”. In terms of visual impairment, these may be the ability to read print, see a sign, or distinguish steps; however, engaging Thomas’ argument, such activities become markers, or the basis, for other activity restrictions. Based upon the perceived ramifications of being bodily unable to carry out these activities, those in positions of power may engage these markers as a denial of rights for persons with an impairment, which ultimately leads to the experience of disability as an oppressive relationship. For example, a visually impaired person deemed unfit to engage with employment by the *National Assistance Act* (1948), due to the functional limitations associated with a medicalised definition, would be disabled should there be a subsequent denial of their right to engage with equipment or alterations which could compensate for the perceived inability to perform activities ‘normally’. As Thomas argues “disability would then lie within the denial of rights, or the refusal to assist in overcoming functional limitations’ (1999, pp.42-43).

However, in addition to the impairment and social setting relationship Thomas examines, drawing on feminist writers such as Jenny Morris (1991) she develops a psycho-emotional reading of disability. This incorporates “other dimensions of socially imposed restrictions...those which operate to shape personal identity, subjectivity or the landscapes of our interior worlds – and work along psychological and emotional pathways...” (Thomas, 1999, p.46). For Thomas (2007), how one feels is never solely down to impairment, instead this is constructed and tended to by the social contexts in which people live. Reeve (2002) notes that one dimension of this is the emotional responses generated by the reactions of

others, such as feeling ashamed or worthless. Therefore, visually impaired people may not only be disabled by external restrictions on physical activities, but also through an internalised psycho-emotional dimension. Consequently, one may construct oneself as problematic having internalised the constructions of disability of wider society. In addition, in terms of visual impairment there are times when it may be painful, embarrassing, and uncomfortable and so to remove the psycho-emotional dimension from this exploration of the student experience of visual impairment would be unhelpful. As Goodley (2014, p.65) contends, this is because “we could understand the psycho-emotional mode of production as a relational, cultural and political one”.

### **Key Theoretical Areas Influencing the Research: Critical Disability Studies and Ableism**

I turn finally to Critical Disability Studies (CDS) in considering key theoretical areas which inform this study. I consider it an approach that can offer productive perspectives on the issues that surround the understanding of visual impairment. The previous section helped to frame visual impairment in terms of medical discourse, the Social Model discourse, from an Affirmation Model perspective, and finally from a psycho-emotional perspective. Whilst all inform this research, CDS engages with an interdisciplinary theoretical stance to examine the lived experiences of disability whilst disrupting more traditional notions of disability, impairment, ability and difference more broadly (Campbell, 2009; Goodley, 2011). The disruption of traditional notions is particularly important here, for, as Goodley states, “if any justification were required for critical studies of disablism, then one only needs to interrogate common-sense ideas that float around disability” (2014, p.3). These common-sense, traditional, taken for granted ideas, form the



background to the critical questions I pose in unpicking the experiences of being visually impaired, being a student and being a visually impaired student.

As Goodley (2013, p.632) also suggests “critical disability studies start with disability but never end with it”, a concept which reframes the complexities of how lives are lived; stating that “Disability is *the* space from which to think through a host of political, theoretical and practical issues that are relevant to all” (ibid. Author’s emphasis). It is this perspective on space that encourages the use of CDS as a tool to understand the lives of visually impaired people within the context of HE, rather than taking as an approach one which seeks to understand visual impairment and impose this as a construct upon visually impaired people within HE. Here, then, the personal may become political and structural, but the personal remains important.

Critical disability studies require an intersectional approach, one which recognises that many aspects make up peoples’ lived experience, considering the interrelation of gender, race, sexuality, class and so on and the axes upon which these intersect. To move away from traditional conceptions of disability using CDS in terms of this thesis involves a critique of an essentialist and narrow view of impairment. In addition, the thesis relates the experience of being visually impaired to the underpinning epistemological positioning about the meaning given to experience and understanding of our lives and the ways in which these can and do constrict and shape our experiences. Drawing on a CDS approach underpins the distinctiveness of this research whilst making the most of the opportunity to explore visual impairment in a way that invests in the uniqueness of individual experience and the collectiveness of shared stories.

CDS additionally rejects the positioning of disability as tragedy (Goodley, 2011) a refutation which my thesis echoes. For me, the imposition of notions of tragedy upon visually impaired people’s lives epitomizes the ways in which society

does not value difference. As Goodley (2014, p.155) further argues, “If the only valid ontology is the sighted one then we are clearly committing a dangerous negation of other ontological positions (or as I like to call them, lives)”. When considered as tragic, visually impaired people are contained and pitied. That their experiences of impairment are sometimes painful and embarrassing but equally may be liberating (Morris, 1991) is not acknowledged or valued. CDS, I contend, encourages narratives of liberation and value.

Consequently, this research will draw on both CDS and discourses around ableism, a term I explore shortly, as lenses in examining the chosen area as well as incorporating principles of emancipatory research. Embedding CDS into my research means understanding disability to be a fluid category which changes over geographical and other space, and historical time, a category in which allows for the examination of the concept of being disabled. Reflecting on the constructions here which depict visual impairment it is apparent that, whilst rooted in a medicalised discourse, it is dependent on the ways in which it is experienced within and around the temporal spaces inhabited. As Shakespeare (2014) contends, the continuum that visual impairment exists upon is related directly to the social space which inhabited at the time, and thus how disability is constructed and how that construction is used. This resonates with the ways in which I conceptualise visual impairment, which acts as a rebuttal of traditional negative discourses. Instead, I recognise the ways in which disability is constructed within a neoliberal society which places immense value on work and participation in order to gain financial reward, or as ensuring that one does not to rely on either state support or charitable philanthropy.

My interest in CDS, then, stems particularly from its approach to politicism, which is distinct from the concept of activism, although, of course, it can be linked

to it. It helps to illuminate issues through analysis of personal and everyday occurrences and through the accounts of individuals. As Goodley, (2014, p.156), summarises it, “Critical disability studies politicises the experience of living with impairment in contemporary society”. It is this politicism which I employ to examine the ways in which research is carried out with visually impaired people, so positioning and locating this project. It also impacts upon how the findings of this study may be used, especially in revealing the ways in which the lives of visually impaired students are permeated with assumptions about the type of person that can be and how they inhabit the normative world. I draw upon the key concepts of ableism and CDS here to explore the ways in which overarching tensions are significant and apparent when visually impaired students inhabit the spaces which are typically reserved for normative and non-disabled people. This is particularly the case when individuals are to embark on a journey intended to develop their capacity to exist within a functioning and work orientated neoliberal society.

Briefly, and in order to contextualise the terms used within this thesis, as I discuss ableist responses to disability, I draw upon Goodley’s (2014, p xi) helpful mapping of what he suggests are anchoring concepts within his work around understanding disability through CDS. Goodley (2014, xi) suggests that “Disablism relates to the oppressive practices of contemporary society that threaten to exclude, eradicate and neutralise those individuals, bodies, minds and community practices which fail to fit capitalist imperative”, thus suggesting that disablism seeks to negate the presence of difference and consequently disability and breeds an ableist response to a disability identity. Goodley (2014, xi) further discusses the notion of ableism as a concept which nobody can match up to if disability is not valued and is therefore positioned as divergent and different to those who are “capable, malleable and compliant”. Ableism thus questions ability and the value of ability, particularly

when imprinted upon a version of personhood as species typical (Campbell, 2009) and deviations of this found as wanting. Thus, examining ableism and disablism together draws us into a reciprocal and cyclic relationship between value, ability, disability and difference. By examining the concepts of ableism and disablism the value placed on ability is highlighted and concurrently by virtue of a binary opposition, disability is not.

As Goodley (xiii) summarises where positionality is added to the mix, in that we ask “why are we here,” a question entirely too broad for most studies of topics such as these, it instead helps us ask, as interested parties within the sphere of disability and disabled people’s lives, what is our purpose of our involvement and interest and how do we intend to engage, then we are offered an opportunity to resettle disability, to examine the concepts and factors which are at play here within wider constructs “not as an individual, medical or administrative phenomenon but as a social, cultural, political and historical construction”. Drawing upon these previous discussions around constructions of disability and impairment I engage with Cameron’s construction and the values held within the theoretical positions discussed to state my understanding of disability as an identity both envisaged negatively by external structures and the people within as a lack or a stigmatised being within the world and also, often misunderstood when discussed as a positive identity, one that values diverse ways of being and the importance of this within a functioning society.

Additionally, I recognise the importance of Goodley’s (2014, p xi) assertion about the meaning of disability as often a signifier, a term which attaches meaning rooted within these understandings and positions actions towards disability differently based on the inherent assumptions attached to the meanings attributed. Therefore, for example in terms of disabled students, disability is the issue, disabled

students are often positioned as other and require alternative or specialised actions and reactions in order to participate within.

Furthermore, when engaging with thinking around disability and impairment, and the recognition that they hold different meanings I again engage with both UPIAS and Cameron's positions around impairment. Impairment becomes something which is categorised and as I will show within this thesis, it is something which is used to assess need and often resultantly open doors to support, thus impairment is a continuum (Shakespeare, 2014, p23 ) difference is recognised yet often still not valued, to be different is to be divergent from the cultural norms associated with ideal forms of personhood and value attributed to ideal standards of personhood. I position myself closely with Goodley's assertions that impairment understanding and positioning could be linked with disablism or the "cultural artefacts of the ableism industry" and therefore challenge what is recognised as the valuable attributes of personhood and participation within society, however I intend within this thesis to steer clear of confusing matters further, and engage with the term visually impaired and blind when they arise or as ways to discuss the experience of the participants within this study, many who refer to themselves as visually impaired or blind. I thus swerve negative connotations which may be associated with these terms by laying out this underpinning discussion to here set out my engagement with these terms.

It is with this in mind that I turn to discuss the importance of such an approach to this thesis.

### **Why Critical Disability Studies?**

It is important that this research takes an approach that examines the complex social worlds existed within. My own position within the research shows

that I am emotionally invested in and, accordingly, 'feel something' about disability, and particularly visual impairment. What that 'something' is was unclear until the lightbulb moment of engaging with CDS. In employing CDS in this study, I both acknowledge and, in some ways, move away from the Social Model, largely as it regards disability as based upon disabling barriers which exclude disabled people from participation (Michalko, 2002). As Michalko (2002) suggests, this does not allow for any conception of the natural body (as the by-product of being human), or indeed impairment, developing as a result of cultural representations. Consequently, visual impairment is not troubled by where impairment is reproduced, experienced, talked about, shared or lived. In contrast, axes of class, age, gender, and ethnicity provide ways to explore these experiences, to trouble how visual impairment is constructed.

Where the Social model focuses on the conditions of disablism, CDS engages strongly with discussions around ableism, something also reflected in this research. Goodley (2014, p.22) summarises ableism in its wider form as:

Ableism's psychological, social, economic, cultural character normatively privileges able-bodiness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies.

As an underpinning ontological base for the thesis, I draw upon Campbell's (2001, p.44) definition of ableism whereby she suggests both what it is and how it impacts upon disability. She argues that it consists of:

A network of beliefs processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and full human. Disability then is cast as a diminished state of being human.

As I have briefly discussed the divide between sighted and non-sighted creates a distinct categorisation of those who can 'see' and thus hold the position of power. To be visually impaired is to be different from the corporeal standard, a diminished state of human and therefore presumably holding a position of lesser value when compared to the able citizen.

Drawing upon Goodley and Campbell's definitions and the way they posit what constitutes an ideal citizen, I engage, in analysing my data, with neoliberal-ableist (Goodley, 2014) perspectives in conceptualising an ideal student, As described by Goodley (2014, p.23), the ideal citizen can be seen as being;

Cognitively, socially and emotionally able and competent, biologically and psychologically stable, genetically and hormonally sound and ontologically responsible; Hearing, mobile, seeing, walking; Normal: sane autonomous, self-sufficient, self-governing, reasonable, law-abiding and economically viable; White, heterosexual, male adult...

Employing the concept of an ableist construction of the ideal student/valued citizen allows an understanding of where students with visual impairment are situated within higher education and why they may experience HEIs as spaces of tension. I engage with this notion across the thesis to conceptualise the place of visual impairment, so troubling HE constructions of VI.

In addition, to understand the experiences of visually impaired students I argue it is also necessary to trouble cultural representations and ingrained and inherent societal perceptions about disability. To do so requires an exploration of the construction of visual impairment, which I examine in more depth in Chapter One, arguing from the outset that visual impairment remains imbued with medicalised and tragically laden discourses that marginalise and other.

## **Research Aims, Questions and Objectives**

My research questions focus on the experience of visually impaired students in the context of higher education. It was my objective to approach their student lives holistically, incorporating data from experiences beyond the classroom. I feel strongly that research needs to focus on both practical and philosophical aspects of experience, to both understand what happens in visually impaired student's everyday life and to what extent their interactions with a range of aspects of HE are influenced by pre-existing narratives. In light of this, I developed broad research questions as follows:

*In what ways do the paradigms of visual impairment and higher education intersect and interact?*

*How do visually impaired 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 visually impaired students in HE?*

These questions helped to formulate the basis of the initial interview schedules to be used with visually impaired students, acting as guiding suggestions and directing participants' thoughts about key events and experiences in HE. It generated the data regarding constructions of the student within HE, of visual impairment and of the VI student which are explored.

In addition, my objective in exploring this experience was influenced by a desire to make the research as participatory as I could (as discussed in Chapter Three). It was my intention to encourage the student participants to shape the research in partnership with me through their feedback on how it represented their



lives and their thoughts about what they felt relevant to add to discussion. This responsiveness and flexibility led, for example, to some discussion in this thesis (see Chapter Six) of pre-HE education. This was incorporated because the participants felt it offered insights into their lives at university and how they understood the experience of study in HE.

## **Chapter One: Representations and Constructions of Visual Impairment.**

In this chapter, I explore how visual impairment and disability are depicted in a number of contemporary and historical contexts. This sets the scene for the thesis in showing how older constructions of disability influence present-day thought. I also use this chapter to suggest that these depictions and constructions may have an impact upon thinking and provision in higher education. Madriaga (2007, p.400) contends that education is an arena that “reflects wider societal attitudes disadvantaging disabled people”, so creating an inextricable link with “an institutionalization of the medical model of disability”. Whilst it could be argued that the focus of participative education is to seek to challenge such institutionalization, that visually impaired students remain significantly under-represented shows how attitudes and practices within, and on the path to, higher education affects their participation. Engaging with Madriaga’s assertion about the presence of disablist and dominant societal attitudes as inherent within education, I examine the construction of these attitudes, considering the influences which have shaped their formation and what this means for visually impaired students as they navigate study at university.

### **Constructing the neoliberal ideal student/citizen**

Building on the definitions of ableism and the ideal citizen outlined earlier, I turn first to neoliberalism and how it contributes to contemporary constructions of the disabled student. Neoliberalism has had an impact upon higher education in that it has driven the sector into increasing marketization, something that has resulted in an approach which draws upon consumerism and focuses on the achievement of standards that may be antithetical to diversity and individuality. This philosophy dominates the underlying principles which dictate the value of participation in economic productivity and which have overseen “public entitlements, such as

welfare and education ... dismantled through an alliance with market freedom...” (Goodley, 2011, p.143). This is because, as an ableist perspective, Goodley (2014, p.26) suggests, neoliberalism “normalises through the constitution of the ideal citizen”, making the “normal an idealisation pursued through transforming economies, restructuring nation states and worshipping the market” (ibid). The ideal citizen, therefore, is one that can actively participate within “and progress through life via individual merits and hard work” (ibid).

How then, if being identified as severely sight impaired brings with it an assertion that that person will be able to undertake no work, can a visually impaired person claim status as an ideal citizen? This is a question outside the remit of this thesis. However, it is clear that the ideal citizen analogy is one that can usefully be employed in discussions of the ‘them and us’ binary of impaired and not impaired, disabled and able. If, as Goodley (2014, p.28) summarises “the expected products of schools [education] are functioning pliant workers and active consumers” then visually impaired students face an uphill battle to overcome the neoliberalist agendas associated with education and employment.

As Goodley (2014) has shown, the ideal citizen can be envisaged through a neoliberal and ableist lens as one that can participate fully in a society that values the ability to engage in employment and other pursuits considered valuable. For visually impaired people, what is valued in such a philosophy can often be unobtainable and unachievable if visual impairment, specifically, and disability more widely are excluded by virtue of being categorised as different or as on the fringes of participation.

Further, the ideal citizen is conceptualised as the corporeal standard, perfect, species-typical, essential fully human, body (Campbell, 2009), that does not fall short of what Mia Mingus describes as this “mythical norm” (Mingus, 2011, accessed

16/8/18), and is rooted within an ableist discourse of “white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability” (ibid). Therefore, for those who are outside of this corporeal standard and unable and/or unwilling to take on board the concept of a homogenised ideal of personhood, the ideal citizen is a problematic construction. For many, the reliance on the corporeal standard as a measure of acceptability further confirms that to be disabled is to be different and is thus unvalued, and unwanted. It is to this end that the conceptualisation of the ideal citizen is a useful tool with which to examine neoliberalism and ableist perspectives yet is not employed as an addition to the theoretical framework engaged within this thesis.

### **Disability legislation and policy**

Current legislation also contributes to contemporary constructions of visual impairment, as it continues to place disability and impairment within an individualised framework, although it is criticised by both academics and activists for doing so. For example, the *Equality Act* (2010) in the UK states disability

“is a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities”.

Noting the language within this definition the act engages with an individualised perception and construction of disability, one which remains focused on the person’s ability to carry out activities in a manner decreed as normal. The language of normality is predominantly oppressive and such wording within national legislation appears to highlight an ongoing allegiance to this individualised understanding of disability.

This reflects the language of other, earlier, legislation and relates to historical definitions of disability. As Drake (1999) suggests, the dominant definitions in Britain throughout the twentieth century are of a medical or personal tragedy model of disability and have predominantly focused around the effects of and limits for participation for those with impairments. Oliver (1990) notes that what is constituted as disability has undergone significant and multiple changes over time, without gaining general approval. This analysis suggests an overall construction of disability rooted in the past, despite contemporary interventions. The definitions of visual impairment are similarly problematic, and the following section examines some aspects of them in order to highlight the tensions and debates they relate to.

Within the UK, a person with a visual impairment is categorised as either severely sight impaired or sight impaired. Severely sight impaired (SSI) was defined within the *National Assistance Act* Section 64 (1) (1948) as being “so blind as to be unable to perform any work for which eyesight is essential”. SSI registration is further noted as being appropriate to be used when a person is “unable to do any work for which eyesight is essential, not just his or her normal job or one particular job” (*ibid*). Contrastingly, Sight Impairment (SI) is not legally defined. Instead, it relies on guidelines derived from the above definition, which state that a person can be classified as severely sighted if “they are substantially and permanently handicapped by defective vision caused by congenital defect, illness or injury” (Department of Health, 2013). Medicalised terminology such as handicapped and defective underpin the ways in which visual impairment are understood negatively within a framework that promotes normative bodies and minds.

Arguably, both national and international historical circumstances may have developed the perceived need for such classification, including the repercussions of

WWII (and the likelihood of significant increases in the number of people who had some level of visual impairment), and the introduction of the Welfare State. However, why such definitions have not been updated is puzzling; for example, the ability to seek and maintain employment appears still strongly favoured despite the ongoing challenges to a disabling society.

Both SSI and SI necessitate that an individual undergo assessment once they have undergone medical testing carried out by registered ophthalmologists, measuring visual function against predetermined useful levels of visual acuity and visual field (Department of Health, 2013). However, as Shakespeare (2014, p.23) contends, visual impairment can be contested as a subjective social judgement, based upon a continuum and a temporal existence which “depends on the definition of what is classed as an impairment, or rather what counts as average – or normal – vision”. For example, the 1948 Act had highlighted an ongoing reliance on categorisations that had been developed in response to industrialisation and so had originated in the early nineteenth century. As society became more embroiled in capitalistic endeavour and individuals increasingly sought work in the newly industrialised towns and cities, those unable to seek work were increasingly reliant on charitable and philanthropic means of support. This meant that categorisation became seen as more necessary, something in opposition to the perceived ability of families and communities to support disabled people within their own localities that had likely been previously prevalent (Oliver, 1990).

Similarly, beyond Britain there are also continuations of categorisation in attempting to define disability. For example, within the International Classification of Diseases (ICD, 2015), visual impairment is classified within 5 separate clinically measured categories ranging from no visual impairment to blindness and blindness with light perception, dependent on levels of visual function. Outside Britain there

seems to be slightly more of an acknowledgement that disability is not straightforward or a singular phenomenon. For example, The United Nations *World Report on Disability* (2011) states disability “is complex, dynamic, multidimensional and contested” and suggests it is an umbrella term which encompasses “impairment, activity limitation and participation restriction”, noting impairment as “problems in body functions or alterations in body structure – for example paralysis or blindness” (2011, pp.4-5). This definition, however, despite showing some understanding of disability and visual impairment, also appears to rely on a construction of visual impairment which places limitation and problematized ability as the domain of the individual.

### **Loss, Tragedy, Fear and the ‘Normal’.**

As noted above, traditional concepts of visual impairment are informed by notions of loss and deficit; some are centred on pity and portray it as something to be fearful of. Other discourses talk of ‘overcoming’; showing resilience or inspiration despite the ‘tragedy’ of sight loss. None of these discourses provide an adequate and all-encompassing description or definition, one that really captures what it is to be visually impaired. The contemporary negative positioning of VI suggests that the work of so many disabled people, academics and the implementation of political changes has not had a large impact upon dominant discourses or constructions. These discourses centre, most of all, on the idea of tragedy and the individual, a position sometimes outlined in moral terms, reflecting a view of disability as a punishment for behaviour considered improper. Such discourses are often rooted within historical constructions of disability that remain in effect in contemporary society. For example, there are periodically debates about whether NHS access should be offered to people whose impairments are perceived to have come about

from alcohol dependence or obesity. Such discourses, perhaps inevitably, also consider the individual in isolation. As Swain and French (2000 p. 573) note:

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 knowledge of the experiences of people with visual impairments, whose identity is founded on being sighted, and who has been subjected to the personal tragedy model of visual impairment.

Visual impairment, when examined from this perspective, is the problem of the individual, suggesting that they are deficient and that their visual impairment is a personal failing that causes the individual problems, not an issue for wider society to consider. This is a position also common in more contemporary ways of thinking, such as neoliberalism, as noted earlier.

Examining this through the perspective of a medicalised discourse would suggest that problems with sight, whilst individual, are in need of cure or rehabilitation. Solutions are typically presented as common-sense and it is argued that such problems can be managed by intervention from medicine. These representations of disability, Brisenden (1986) argued, are the myths of disability, reproduced by those in expert positions, such as medical professionals. Paul Hunt (1966, p.8) further expands on ways in which disability is constructed in terms of being “unfortunate, useless, different, oppressed and sick” and how these constructions are consistently at play within the ways in which disabled people are on the fringes of social worlds. He discusses disabled people when constructed as being sick and in need of cure are often subjected to terminology that relates sickness to morality, “we talk of a good or bad leg, of being fit or unfit, of walking properly, of perfect physique” (Hunt, 1966, p.16). As Hunt shows the ways in which disability is discussed can underpin the ways in which disability is understood and thus how it is written into the fibres of society.



This is related to, as Cameron (2014) suggests, the way that lives are subjected to a multifaceted system of established factors and influences which position understanding of ourselves and others and the place within these relationships. Those that have the greatest bearing, he contends, are those that are conveyed by the most powerful structures and groups and are made up of common-sense ideas and authoritative influences. This creates a normative position whereby those who are at one end of the visual impairment continuum with sight within “normal” ranges are divided from and are at the other end of the scale from, those who do not, creating a divide between sighted and non-sighted.

Engaging with Goffman in his seminal work on stigma, Titchkosky (2003) states that Goffman’s work places stigma as a social phenomenon that exists between people, as an attribute which marks out difference, yet this difference does not demand stigmatisation, instead it is the ways in which this difference is constructed within interactions and within societal understandings of disability and difference that creates a stigmatised way of being.

Correspondingly, Drake (1999) contends that those who hold the balance of power, in this case those who can delineate what ‘normal’ sight is, are also able to pass judgement on what and who is different: that being specifically in this case those who do not achieve the categorisation of normal sight. By doing so, the construction of normalcy is compounded and places the ‘problem’ of impairment as the issue of the individual. In terms of those in positions of power Michalko (1992, p.133) states that identification as disabled is bound within complex representations and that “particular images of disability flow from the modern idea of the expert, from which flows images of disability steeped in an ideologically based version of knowledge about disability”. Formed by non-visually impaired people, these expert positions create definitions of severe sight impairment and sight impairment and can

delineate and in effect construct what is recognised 'normal' sight and thus what is not.

These powerful and dominant discourses and constructions pervade society and enforce a position for the visually impaired person whereby they are considered to be outside of the normative, non-sight impaired standard of personhood. The VI person is expected to take on board a medically dominated definition of what visual impairment is measured as and the connotations associated with this. As Titchkosky (2003, p.135) states;

The most authoritative representations of disabled people arise from medical and/or therapeutic disciplines, and the social sciences. Anyone who is to be regarded as 'in the know' about disability must show they know that *it is a problem*, and the more details they possess of the problem thing, the better.

Medicalised, individualised, expert knowledge about disability tells us what traits and characteristics are valued most highly and that those who do not match up to these are considered less valued than others. These ideals are produced through values practiced in what Goodley (2014, p.23) describes as,

disabling or ableist societies; societies governed by biotechnologies, and new potentialities of eugenics...cultures that value mobility, hearing, speaking, sight, bodily control and comportment... value forms of cognitive ability, mental health, meritocracy and entrepreneurship

Visual impairment, when examined through this conceptualisation, is shown as wanting. This conforms to what Michalko (2002, p.18) states as the overarching view of disability, that it "is not valued in contemporary society, it is not seen as normal, and it is certainly understood as a problem."

## **Disability Identity and Oppression**

Disability identity is typically a multifaceted amalgamation of conflicting and oppressive beliefs and practices which may construct disability along the lines of the subtitle of Goffman's (1963) treatise on stigma, as "a spoiled identity" and which relies heavily on a deviation from what is considered 'normal'. As Fromm (2001, p.119) suggests "the person who is able to fulfil the social role he has been given and to work in the fashion that contemporary society requires of him" occupies the position of 'normal'. When taking on a disabled identity, this invokes, from others, stereotypical assumptions about disability such as being poor, or a victim, or tragic; to brave or inspirational, overcoming adversity and tragedy (Rieser and Mason, 1990), all which position the individual as different, an identity that often becomes oppressive.

Young (1990, p.41) observes that "as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media stereotypes, and structural features of bureaucratic hierarchies and market mechanisms –in short, the normal processes of everyday life", injustice is experienced by disabled people. Young (1990, p.41) further notes that the "disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society" creates oppressive practices and thoughts, even amongst well-meaning responses to disabled people. As Goffman (1959, p.20) suggests, "others, no matter how passive their role may seem to be, will themselves effectively project a definition of the situation by virtue of their response to the individual and by virtue of any lines of action they initiate". Whilst Goffman suggests that these definitions are ordinarily attuned to each other and thus do not initiate contradictions, he also states that "participants contribute to a single over-all definition of the situation which involves

not so much a real agreement as to what exists but rather a real agreement as to whose claims concerning what issues will be temporarily honoured” (1959, p.21). In response, Zola (1982, p.244) asks “Why [has] a society been created and perpetuated which excludes so many of its members?”, a question Michalko (2002, pp.15-16) reflects upon, contending that “exclusion, intentional or not, is a political act and, therefore, a choice... society has decided to include disability in particular ways”.

In addition, Campbell (2009, p.7) discusses the ways in which a disability identity requires the disabled person “to emulate the norm... required to embrace, indeed, to assume, an ‘identity’ other than one’s own”. She further contends, “I am not implying that people only have one true or real essence. Indeed, identity formation is in a constant state of fluidity, multiplicity, and (re) formation” (ibid). For disabled identities, however, this fluidity can be curtailed by cultural and societal expectations around disability.

### **Contemporary Cultural Representations of Visual Impairment**

Visual impairment in contemporary British society can be examined through a huge number of cultural representations, for example, the RNIB (2015) campaign ‘See the Need’. This UK based campaign was aimed at raising awareness about the lack of specialist ‘eye clinic liaison workers’ (ECLO’s) within ophthalmology departments and was shown and spread via social media. The campaign incorporated contributions from actors who discussed their fear about potentially becoming blind or losing significant aspects of their sight. In my earlier working life, I had experienced the reliance by charities on medicalised and tragic positioning of visual impairment as means with which to draw in support, and ultimately funding, but that a comparatively recent campaign engaged with a similar rhetoric simply highlighted to me the ongoing negativity associated with visual impairment. In

addition, the campaign also drew heavily on common-sense approaches to disability as tragic and limiting.

I incorporated the RNIB campaign into sessions with undergraduate and master's level students both within and beyond Disability Studies, asking them to consider how this representation might, as part of a dominant societal discourse, influence understanding of visual impairment and blindness. Their responses were largely in agreement with what the campaign showed, revealing a significantly negative understanding of visual impairment and suggesting that the campaign taps into traditional conceptions of people with visual impairment.

Similarly, Bolt (2016) contends, in his critical analysis of the campaign, that the portrayal of visual impairment as tragic and unfortunate signifies a one dimensional and exclusionary understanding. He states that the depiction of well-known actors closing their eyes and talking in terms of fear and pity, compounds the already existing negative assumptions about, and constructions of, visual impairment. For Bolt, the representation by the RNIB is contradictory in terms of the way in which it prioritises organisational need, that of funding for the charity, over that of the people it represents.

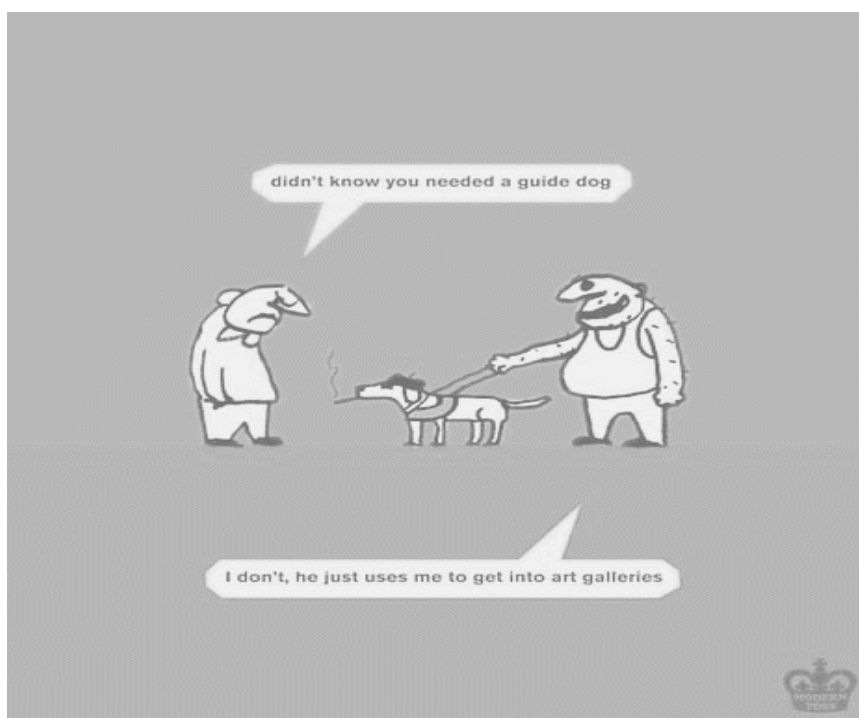
Charity, Hughes (2010) contends, is an institutional expression of the personal tragedy theory of disability that directs both social interaction and policy. Hughes (2010) further argues that disabled people are seen as dependent on and in need of charity as a common-sense approach to disability, thus it is unsurprising that whilst many attempts have been made to challenge the ways in which disability is constructed, the role of a disabled person remains constant within the rhetoric presented by charitable organisations. As Goodley (2014, p.122) suggests, "the question is, of course, who wants to live as a charity case? Sadly, if we are to accept that the collective unconscious of normal society views disability-as-charity, it is

difficult to see how disability can be wrenched free from such an embedded worldview". In relation to my teaching sessions, many of the students, despite their informed position as Disability Studies specialists, or students interested in wider social inequality, felt that even though they recognised the negativity associated with the positioning of disabled people as dependent that this was an inevitable aspect of being disabled. This highlights the ways in which dominant discourses about disabled people are accepted as common-sense and the influence such discourse bears upon the constructions of being disabled generally.

Scott (1969, p.3) in his study of the construction of blindness in America argued that organised intervention, such as that by agencies who work with visually impaired people, plays a major role in determining the social role blind/visually impaired people are expected to play. This links with what French and Swain (2008) suggest which is that disabled people are often thought of as a homogenous group and thus it is presumed that they are likely all share the same characteristics. In the case of this research, people who are visually impaired are often homogenised into a group called 'The Blind'.

A brief search about visual impairment shows there is a large amount of material informing and reflecting cultural representations. Examples in 2017 and 2018 included a media story on visual impairment where that experience was equated to feelings of going 'mad' (BBC, 2018) and an abundance of articles proclaiming cures for blindness (including ones on genetic modification), offering stories of 'inspiration' or 'loss', and a lot of humorous items about the shortcomings of being visually impaired. The cartoon reproduced here, for instance, depicts a guide dog complete with beret and smoking a cigarette (signifiers here of a kind of art connoisseurship and 'hipness'). When the owner, whose vest connotes 'commonness' and ignorance, is questioned about using a guide dog he responds

that the dog uses him to get entry to art galleries. This, it could be suggested, stereotypically connects ignorance with visual impairment in terms of clothing, but also by positioning the guide dog as more culturally engaged than the person accompanying them.



(Modern Toss on National Guide Dogs Week, *The Guardian*, 7 October, 2017) (Figure 1)

Generally, these pieces conform to dominant discourses about visual impairment. One of the few examples that worked differently was an opinion piece on access issues by Cronshaw in *The Guardian*. It centred on a video taken by a fellow commuter of a guide dog owner's experience of being barged past on a London Underground escalator. Cronshaw drew on his own experiences as a visually impaired person, as well as drawing on the evidence of the video, before concluding that whilst there were hopeful signs, "blind people are still seen as a problem". The difference is that this latter article is a personal piece, by someone with appropriate experience, which does not homogenise and acts as advocacy and

self-advocacy. In contrast, the vast majority of the items consider visual impairment as an abstract and are informed by each other, not by reference to lived experience.

In literature there are a multitude of texts which have a visually impaired or blind character as outlined by Bolt (2005, 2006). The majority are secondary characters, although others, like the Marvel comics superhero 'Daredevil', are the main protagonist. Whilst that character is a hero, many are villains, reflecting an ideology particularly informing literature from the nineteenth and early twentieth centuries in linking physical 'imperfections' explicitly with moral ones. That visually impaired people are portrayed inaccurately, either as corrupt or relying on super senses is discussed by Man (2018), a blogger who shares his experiences of being visually impaired. Man suggests these depictions negatively inform people and lower awareness.

Man (2018) also engages with other myths about blind and visually impaired people that appear in fictions across a range of media, including seeing by touch, particularly by touching people's faces. This notion may seem to be outdated, however, drawing on my professional experience, I can confirm that more than once a newly visually impaired person, arriving to undertake a course to assist with accessing technology, would tell me that they were nervous to meet other visually impaired people, as they were afraid everyone would have to touch and have their faces touched. Such misconceptions stem from misinformation derived from dominant discourses as shown in cultural representations.

Cultural representations of visual impairment draw heavily on one particular dominant discourse that presents visual impairment and blindness "in a world socially organised through and by some version of 'seeing'" (Michalko, 2010, p.1). As Michalko (ibid) contends "our blindness time is always set to culture standard time", the latter setting the standards for the ways in which we experience blindness;



“to ophthalmology, to terror, to denial, to anger, to self-pity and finally to acceptance. Blindness time is the time to set its time to rehabilitation, to a person that merely happens to be blind, to being synchronised with the time of being “like-everyone-else”. The majority of the stories about visual impairment and blindness mentioned earlier, then, can be seen as demonstrating culture standard time, setting the scene for how blindness is experienced.

### **The ‘Hypothetical Blind Man’.**

These cultural representations, and the homogenising of all experiencing a huge range of visual impairment connects with a figure which Kleege (2005) identified, a personification of the “Hypothetical Blind Man”, often abbreviated to “The Hypothetical”. This construction tells what can be known about blindness and those who are blind. Kleege contends that “The Hypothetical” plays a “useful, although thankless role” (2005, p.180) subjected to investigations around the way experiences affect life and embodying beliefs about what visual impairment is:

The emotional baggage he hauls around with him comes from other cultural representations of blindness... His primary function is to elicit a frisson of awe and pity which promotes gratitude among the sighted theorists for the vision they possess (ibid).

The hypothetical blind man also plays an important role in understanding the ways in which representations of visual impairment and blindness are positioned regarding the type of person that a blind or visually impaired person can be. For Schillmeier (2006, p.476) those with a visual impairment are constructed as having:

[T]he highest grade of imperfection and incompleteness of knowledge: deprived of colours and light, the blind man cannot understand the idea of light, lacking quasi-natural *communion* of sight, light and ideas, the blind man has nothing to offer other than words, a messy understanding and highly deficient knowledge, as opposed to the effective, clear and distinct *mass* of knowledge produced by the sighted.

Similarly, Kleege (2005, p.182) suggests, the usage of the term 'blind' in daily interactions and language and the connotations it holds such as "inattention, prejudice or ignorance" contributes to the ways in which low expectations are held about visually impaired people. Along with Michalko's depiction of culture standard time and the time for blindness, Schillmeier's and Kleege's unpacking of a dominant construction of the blind person shows how heavily loaded they are. These constructions conjure darkness, passivity, ignorance and reclusiveness.

Because of these constructions, as Bolt (2005, p.544) argues, "Individuality is displaced in favour of a jaded representational construct 'the blind'. This construct does not only imply the existence of a homogenous group, but one that is antithetical to the sighted, deviant in relation to a perceived normalcy". The ways in which visual impairment and blindness are constructed create a monolithic stereotype, which continues to inform thoughts and beliefs, he argues, referring us back to the homogeneity mentioned earlier.

Finally, for Bolt (2005), given homogenised conventions and continuous assumptions about the likeness and sameness of all types of visual impairment, the experience of being visually impaired in an ableist society is disabling. The ways in which visual impairment is constructed through antithetical renderings of sighted and non-sighted, the seeing and the blind, Bolt (2006, p.550) contends is "simplistic and erroneous... and within the dominant ableist discourse the former takes political precedence over the latter". Therefore, language around visual impairment draws upon an underpinning perception of difference and power inherent within this juxtaposition. Thus, wider interactions with visual impairment as a construction draw upon such subtle and perhaps unconscious ableist assertions.

## **Passing as disabled or passing as sighted in education.**

To take this construction of visual impairment on board as a disabled person would necessitate that the individual work around the many underpinning injustices and perform according to a notion of the norm, in effect, 'passing'. However, this can be problematic, for as Titchkosky (2003, p.69) notes, "Passers are regarded as deviant people trying to achieve, or even eke their way back to, normalcy". In terms of the experience of visual impairment and passing Titchkosky (2003, p.70) comments that:

passing means knowing: it means knowing the minutest details of how everyday existence is orientated to the expectation that sight is an ever-present feature of that existence: it means knowing the customs, habits and signs of seeing people.

In terms of the ways in which visually impaired people are able to 'pass' they are required to know the ways and means with which sighted people engage with the world and how to replicate this without sight. Such actions thus 'allow' visually impaired people to 'pass' within their interactions within the world.

In educational terms, involvement as a disabled student in higher education also requires the negotiation of 'passing'. To access DSA students are pathologized by their impairment, however for some students there is an unwillingness to associate with a disabled identity (Riddell, Tinklin and Wilson, 2005; Barnes, 2007; Riddell and Weedon, 2014) for fear of stigma (Goffman, 1963) and, as indicated in Beauchamp-Pryor's (2012) research, due to the perceived barriers that this may construct between the disabled student and non-disabled peers within their cohort. For disabled students with 'hidden' impairments there may be less need to engage with a notion of passing as there are less obvious indicators.

However, engaging with mobility aids such as a guide dog or long cane mean that some visually impaired students are prominently displayed as such, and as Michalko notes in terms of his partnership with guide dog Smokie, the visual representation of blindness is shown through this partnership: “Smokie’s presence in his harness depicts my blindness to the world” (Michalko, 1999, p.9). Linking back to stereotypical blindness, or ‘The Hypothetical’, Michalko (1999, p.39) later discusses how, accompanied by Smokie, they become symbolic or abstract, not ‘real’ or individual, stating,

Dogs as guides symbolize a version of blindness; when most people see a dog in harness, they also see a blind person. Typically, however, they do not see this “blind person” as an individual with particular hopes and fears, likes and dislikes, anxieties and aspirations, but as a representative of the collective understanding of blindness. That is, they see their society’s conception of blindness rather than an individual blind person.

Michalko’s comments here suggest how notions of passing can be about inhabiting a societally acceptable construction of visual impairment, rather than passing as sighted. This is based around the ways in which visually impaired people are able to negotiate the most obvious or dominant representations of disability. For some visually impaired students then, passing involves an acceptance of difference that does not upset the status-quo, a performance rooted within the stereotypical, rather than individuality, something that not all will willingly engage with.

### **Constructing disabled youth**

Higher education is a dominant domain for young people, at least of those who are perceived as making their way in the world in accordance with neoliberal ideology. This is not an area that intersects necessarily, or fully, with the experience of being a disabled youth as this group are under-represented in HE, as has been flagged up, and will be explored further in later chapters. There are problematic

cultural constructions of all young people, as Robinson (2010) discusses regarding a dominant discourse demonising young men, but in the case of disabled youth these constructions take a different form.

As Hughes et al (2005) note, the construction of identity of disabled youth is not necessarily formed by young, disabled, individuals. Indeed, they argue that “identity may be beyond the control of the individual and may in fact be re-enforced and even predicated upon forms of social and spatial organisation” (Hughes et al, 2005, p.6). As it can be difficult to break away from these processes “they may, at the very least, circumscribe one’s project of self-identity” (ibid).

Typically, to become a university student means engaging with a traditional route through education that begins in early childhood and continues throughout childhood and adolescence. In relation to my research participants, I examine how the life experience of children and young people is informed by cultural and societal expectations of what childhood and youth are throughout this thesis. Whilst I do not employ developmentalist approaches in analysing the interview material, as they rely heavily on ableist constructions of normative development, I do use them to point out cultural and educational ‘norms’. The generalised concept of ‘ages and stages’, for example, which has become an accepted common-sense view of childhood for many child professionals, posits child development as a series of cognitive stages and physical steps through which the child progresses to reach the culturally desired outcome of competent adulthood. Failing to achieve these steps at the ‘correct’ age, means professionals may position a child and their family as in deficit, as incompetent and problematic, othering them, which has clear implications for young people considered disabled (NHS, 2017).

In addition, the neoliberal ideology around the ideal citizen and the significance of the free market, as seen earlier, has implications for the construction

of disabled youth. Hughes et al (2005, p.5) note that young disabled people's participation in consumerist activities is likely to be "mediated by impairment", unlike their non-disabled peers, who can negotiate and participate from a place of unlimited choice and freedom. By implication, this includes marketized higher education.

Hughes et al (2005, p.6) also argue that consumerism is about engaging with objects and services that are sold as embodying "youth, vigour, beauty and so on", so excluding the disabled body, which "is measured in negative terms relative to the aesthetic criteria that dominate judgements about bodies in consumer culture". This can be seen in the marketing for most universities, which typically present an idealized educational consumer. What Hughes et al conclude is that consumption is "designed" as an object that is alien to the carnal constitution of disabled people and young disabled people in particular" (ibid). Thus, whilst non-disabled young people can exercise freedom and choice about the ways in which they consume higher education, young disabled people face "an exclusionary mechanism built into the semiotic fabric of lifestyle and choice" (ibid).

## **Conclusion**

In summary, this chapter has explored dominant constructions of disability and of visual impairment relevant to the thesis. Cultural representations of visual impairment bring with them many connotations; of fear and darkness, of being on the margins of society, of being non-normative and deviant. There is also a homogenisation of all people with visual impairment into a singular, isolated figure, who is to be pitied and read as tragic. Legislation, in addition, also tends to homogenise and remains influenced by understandings of visual impairment from previous centuries.

Further, the construction of the ideal young person, citizen or student in a neoliberal context has at its centre a set of exclusions. Consequently, one may experience oppression, or engage with some form of passing. These various kinds of representation, considered as a whole, offer stereotypes that are visible in the accounts of the research participants. Examining these dominant perspectives on disability highlights a number of factors, including that there are a range of different lenses that are potentially useful in understanding constructions of visual impairment in HE.

These constructions, stereotypes and dominant discourses reflect medicalised views that place the problem of disability in the realm of the individual and the onus on cure and rehabilitation, constructing the individual as other, not 'normal'. This medicalised discourse had, inevitably, to be negotiated by all of the research participants. In contrast, the Social Model offers a perspective whereby social factors are seen to oppress and limit participation, as the various discourses above suggest, again something which will be explored in relation to the experiences of individuals. In this way, key approaches, theories and representations intertwine in the research.

Finally, this chapter has begun to explore ideological drivers regarding the current state of higher education and how they may be seen as implicated in creating tensions and issues for visually impaired people who want to go to university.

## **Chapter Two: Reviewing the Literature. Students, visual impairment and higher education.**

Engaging with previous constructions of visual impairment allows one to illuminate the construction of the visually impaired student and identify the influence this has (or has not) upon the HE context. This informs the focus and selection of what appears in this literature review. As I argue, the visually impaired student, whilst sharing many characteristics with other disabled students, occupies a distinct subject position, and so their experiences are also distinctive.

This chapter examines literature that focuses on both disabled and non-disabled students. It looks at whose experiences are addressed regarding study at university and what aspects of the student experience dominate research. It covers policy alongside academic literature as the two are often intertwined, with academic study commenting on or critiquing policy. I begin by outlining why HE was chosen, then move to some statistically focused material regarding visually impaired students in HE. After that I examine existing literature which considers disability and the university, hierarchies of impairment and that which addresses the experience of being a disabled student. There is only a small amount of research that focuses on visually impaired students' perspectives, but much more is written about being a disabled student generally. I draw upon this to inform the subsequent sections of this chapter. This helps to establish where my research lies in the field.

I will then focus down on the small amount of material specifically addressing visually impaired students. That there has been little written specifically in relation to the experience of being a VI student indicates that there is a gap in the literature. Addressing this gap is what makes this thesis distinctive and original. This section also explores dominant discourses within HE about the student, which have



generally not been explored in relation to students who are visually impaired, but nonetheless have an impact upon their experiences as students.

I also engage in this chapter with research establishing a generalised conceptualisation of student identity, building on work in the previous chapter (pp.37-39), exploring in more depth the ways in which it has developed and juxtaposing this with the ways in which a conceptualisation of visually impaired student identity has similarly, or not, developed. I begin to show how visually impaired students are required to take on board existing conceptions of student identity which do not take their specific experiences and needs into account. To fit into higher education, then, is to potentially negate key aspects of what makes one an individual. Through this juxtaposition, I illustrate how visually impaired students are consistently required to renegotiate their place within higher education and how existing conceptions about visual impairment delineate what visually impaired students are permitted to be and the spaces they are 'allowed' and expected to inhabit.

Finally, in this chapter I explore research that expands on the ways that higher education conceptualises the 'ideal' student through an approach based on an ableist perspective of the normative student. I also show that whilst this normative student has changed in many respects from earlier constructions of the traditional student as white middle-class male, it is still limited. In doing so look at literature addressing accessibility of resources, learning environments and employability. I thus explore how, despite the attempts to diversify the student population, neoliberalist values from both within and beyond HE around the value of conformity and ability to gain meaningful, financially rewarding employment are increasingly prevalent, forcing conformity and excluding those who do not.

## **Why choose to address students in higher education?**

I begin here by briefly explaining why the context of HE was chosen for the research rather than schools or other settings. The choice of HE as is linked to comparatively recent shifts in the sector that mean that the student experience has changed dramatically. Collini (2015, p.29) argues that contemporary higher education in the UK is being “remodelled in accordance with so-called ‘free-market’ ideology, in which students become ‘consumers’ and the measure of universities’ success becomes almost entirely economic”.

This represents a refocusing in the sector away from the ideology underpinning the Robbins report of 1963 which called for the expansion of universities so that “courses of higher education should be available for all those who are qualified by ability and attainment to pursue them and who wish to do so”. (Education in England, no date).

The significance of the report is also clear from what Spencer (2015, p.29) identifies as the “four famous paragraphs”, which are highlighted below:

Para 25. We begin with instruction in skills suitable to play a part in the general division of labour ...

Para 26. But secondly, while emphasising that there is no betrayal of values when institutions of higher education teach what will be of some practical use, we must postulate that what is taught should be taught in such a way as to promote the general powers of the mind ...

Para 27. Thirdly we must name the advancement of learning ...

Para 28. Finally there is a function that is more difficult to describe concisely but that is none the less fundamental: the transmission of a common culture and common standards of citizenship.

These points show a vision of university education as functional in part, but as predominantly about personal growth, seen as inherently good for wider society, as

fulfilling a kind of cultural work about identity, and not wholly about student employability or monetary profit for the institutions involved.

Whilst many changes and adaptations have occurred in HE since Robbins set out these objectives, they still inform the thinking of many contemporary students and lecturers, setting up tensions within individual HEIs and the sector generally regarding market forces. Whilst much of the parliamentary engagement with HE was not as altruistic as that of the 1960s, it typically promoted HE as a force for good and for societal change. However, successive UK Governments have also perceived HE as a tool with which to promote economic growth by opening up participation to greater numbers of the nation's youth and adult population.

Examination of the sheer volume of bills, white papers and acts that have influenced and shaped the higher education landscape reveals a huge range of varied visions regarding the issue of what higher education should be for, shaped by the political aims of whatever government is in charge at any given time. For example, in the 1980s, the Conservative government, informed by the first major flowering of neoliberal ideology in the UK, enforced some external assessment of universities to ensure that they were producing viable and economically engaged graduates, something described by historian of higher education policy, Shattock, as the start of "a long march from a fully subsidised higher education to a privatised one" (2012, p.7). This was accompanied by stringent cuts to funding by the government, something that enabled an increased amount of indirect control of who entered university, what they studied, and what was valued. This shifts the perception of the role of HE away from Robbins' vision and into having a purely economic function, rather than one focused on personal growth and social cohesion.

Spencer (2015, p.28) contends that even now, the "the retreat from Robbin's values has been a largely unacknowledged one" yet changes initiated in the 1980s

have been sustained and expanded. Indeed, it could be argued that Tony Blair continued the neoliberal project in HE through the development of a fee-paying structure, as noted by Reay (2008), despite his government's presentation of education as culturally significant. More recently, at the time of completing my own undergraduate programme in 2010 the Conservative/Liberal Democrat coalition government had come into power and the issue of the cost of higher education was at the heart of much debate, including how it might change potential student behaviour, as discussed by Wilkins, Shams and Huisman (2013). The cost to the student of their participation was increased significantly. I did not directly experience the increase of fees from £3000 to £9000 per annum yet the pressure that this put upon not only students, but also academics, became increasingly apparent. For many the students' protests against this increase in fees was justified, yet for others there remained a debate about the value that should be placed on the cost of getting a degree and the ways in which having an undergraduate degree related to increased earning potential as discussed by Jones (2010) and Bunce et al (2017). The division between recent practice, ideology and that of Robbins, seems cemented in place.

This is relevant, as I discuss in the final chapters, given that many of the participants I spoke to both engage with the idea of higher education as a means to improve their opportunities within the labour market and also maintain a belief that education itself is that admirable objective of a transmission of a common culture, personal growth, and common standards of citizenship. However, as stated, being an active part of the labour market is increasingly posited as the key outcome of higher education. As suggested, for visually impaired people, there are many issues regarding their participation within society generally and I would argue that these are replicated within the arena of higher education in general and in individual HEIs.

Currently the higher education sector is undergoing more change which may well drive it further into monetization and an accountability which demands concrete 'measurables'. As Collini (2015, p.29) notes the increasing regulation and need for adherence to externally stipulated measures of quality steers higher education towards a position whereby "only that which can be measured can be considered objective" and thus as a marker of quality. In comparison, the Robbins report engaged with infinitely harder qualities and outcomes to quantify, and the erosion of the purposes of HE that report outlined indicates the huge alteration that has taken place.

This shift towards the market could also be said to be demonstrated in the new regulatory body, the Office for Students (OfS, 2018) established after the implementation of the Higher Education and Research Act (HERA) (2017). The OfS website emphasises a competitive market, student choice, and the government as a stakeholder. It is also said to be empowered to intervene when the market is failing in areas such as equal access. However, there was originally no student representation on the board, nor were the National Union of Students (NUS) formally involved. Consequently, it will be interesting to see how their commitment to equal access is defined and applied given a seeming reluctance to engage with young people and their representatives. Further, Goodley (2016), discussing the impact of neoliberalism generally upon the disabled child suggests that all policy formations contain contradictions that cause problems for those children. Given the tensions between competition and equal access, this comment illuminates how the work of the OfS may influence education for the disabled young person.

HE was selected, as I have stated, because of the shifts occurring within the sector. All of education is impacted upon by the ideologies informing the actions of governments, but in this sector the student is much more directly aware of the

economic and ideological factors that are involved, an awareness made more acute through the introduction and growth of fees. In addition, for visually impaired students to participate in higher education necessitates their adherence and acceptance of externally posed requirements, to fit within certain constructions and negotiate dominant discourses, in order to gain access and to achieve within the current system. This, I would argue, has sensitised them to the ways that higher education is conflicted and thus conflicting, for, as Collini (2015, p.30) states:

We have reached the position where to describe the primary purpose of universities in terms of the deepening of human understanding about the social and natural world is dismissed as highminded waffle, whereas to say that such activities indirectly contribute so many billion pounds to the economy is considered a powerful democratic argument.

### **Visually impaired students in Higher Education**

I next turn to what data is available concerning visually impaired students in HE in the UK. They make up a very small percentage of the total number of students. As of 2013/2014 there were 1,065 students registered and identifying as visually impaired (HESA, 2016) across all levels of study. This is approximately 0.046% of the total student population, recorded at 2,299,355. Disabled students totalled 83,410 with visually impaired students making up 1.3% of this total amount approximately. These statistics do not accurately summarise the number of visually impaired or blind students currently within higher education. However, there are few other indicators available with which to estimate numbers of students.

Indicators within this statistical set combine students who identify as having two or more impairments together, which may serve to make the figures less accurate. Thus, should a VI student identify as both visually impaired and as having another impairment neither is recorded specifically and so the individual student

cannot effectively be identified as they are placed in a catch-all category of dual impairments. In addition, all students are rightly able to choose whether to disclose impairment(s) to their HEI, and non-disclosure would lead to the omission of any such numbers from official statistics. Despite this, examination of the official statistics available suggests that visually impaired students in higher education appear to be an under-represented group.

Whilst the number of disabled students participating in HE has risen, generally, and has been noted as a significant change (HESA, 2016; HEFCE, 2016) an increase in visually impaired students appears not to have developed comparatively. I have located no literature that examines why this might be. That this is the case makes this study significant in analysing current and recent visually impaired students' experiences. Within the UK there were around two million people "living with sight loss" as of 2015, with this figure estimated to increase to around four million by 2050 (Royal National Institute for the Blind, 2016). This figure includes around 41,000 young people under the age of 25 as of 2013 (Royal National Institute for the Blind, 2016). Whilst these figures are estimations, they show a projected increase in the numbers of visually impaired in the approaching decades and highlight that a reasonably large cohort of visually impaired people exist with the potential to embark on study in higher education. However, this does not mean that they will necessarily choose to study, and it is not within the remit of this study to examine the motivating factors or lack thereof for VI people to engage with Higher Education.

It is apparent that whilst there appear to be some visually impaired students within Higher Education, it is difficult to identify a true picture due to the convoluted ways in which these numbers are reported and the muddying of the waters around dual impairments. Consequently, my sample was accordingly on a small scale, as

discussed in the Methodology chapter. Whilst higher education must provide opportunities for visually impaired and disabled students, the numbers imply that not all of those who are capable of, and may wish to, study at university are being supported in this ambition.

### **Participation, Disability Studies, policy and rhetoric in higher education**

Policy directives and their translation into practice have often been contentious within higher education and education, generally, given that there was no requirement to make non-discriminatory provisions towards disabled people until the introduction of the 2001 Disability Discrimination Act (Tinklin, Riddell and Wilson, 2004). The introduction of the earlier DDA in 1997 made it unlawful for disabled people to be discriminated against yet did not extend to education. Engagement with the experiences of disabled students within higher education did not immediately follow. The Deering Report (1997) did not include recommendations about disabled students despite focusing on education as a means with which to develop a learning society. The exclusion was perhaps due to a generalisation about provision for all students, rather than distinct categories of student. However, there is an economic justification within the report of the importance of increasing participation to mirror that of other countries, in order to meet the demands of the future workforce. The emphasis on work, combined with cultural constructions of disability as non-productive, perhaps highlights the ethos that underpins the absence of recommendations about how disabled students could be included.

Whilst disabled students remained excluded from specific objectives to improve access to higher education, pressure from voluntary groups developed a significant focus on the participation of disabled students and as such specific recommendations emerged, such as the improvement of the offer for DSA and to fund learning support in HEIs (Tinklin, et al, 2004 b). However, Beauchamp-Pryor



(2012), when discussing the ways in which disability discrimination legislation was implemented within HE, notes the ways in which the voices of disabled people were absent from the consultative process. Instead the views of disability charities were sought, a process many activists and academics argued was “mis-representing the priorities, values and views of disabled people themselves” (Beauchamp-Pryor, 2012, p.286). That approach ran the risk of repeating what had come before, a top down organisational approach to the provision of disabled student’s support. As Oliver (1990) summarises, those organisations, particularly their non-disabled staff, who claim to represent disabled people were likely to “articulate their own assumptions about the needs of disabled people rather than the needs of disabled people as they themselves express them” (Oliver, 1990, p.105).

The recent Higher Education Funding Council England (HEFCE, 2017) report suggests that there has been an improvement of and progress towards a more ‘inclusive’ environment. However, their report also argues that many institutions have some way to go in terms of their organisational responses to disabled students as “typically, policies cover assessment, teaching and learning and student support rather than the student experience and inclusive curriculum design” (2017, p.2). There was also an identified need for changes to the culture within organisations and particularly a need for staff to become more proactive about buying in to the promotion of participation. This highlights continuity with what Barnes (2002) discussed regarding a disconnect between higher education and the disabled community and the importance of bringing these together in order to ensure that higher education produces meaningful and well-informed knowledge built upon the experiences of disabled students themselves.

However, as Barnes (2002) also noted, the increasing market forces encroaching into the higher education sector challenged the ways in which the

knowledge produced by the academy is valued. He argued that the increased pressure on universities to sustain economic viability and maintain a competitive opposition against each other has damaged the transformative facility of higher education. All the same, whilst Barnes urged caution in relation to the relationship between disabled people and the knowledge produced by the academy in terms of social citizenship, he suggested that there may be call for “cautious optimism” (Barnes, 2002, p.140) that universities could strengthen and facilitate the participation and inclusion of disabled people into mainstream society. Whether this optimism was misplaced is suggested in the findings of this thesis.

As the recent HEFCE report (2017) notes, if the higher education sector is increasingly developing strategies that promote the participation of disabled students within universities, it is imperative that it engages more deeply with the communities of disabled students and academics, to ensure that despite the increasing marketisation of higher education, disabled people remain active stakeholders. The report noted that disabled students are often singularly represented by members of the Students Union within senior management boards. However, these run the risk of being limited within the policy process by what Beauchamp-Pryor (2012, p.288) suggests are the “professional perspectives, notions of expertise and attitudes towards the capabilities of disabled students to be involved”. This offers continuity with French (1994) who stated that “traditionally, professional workers have defined, planned and delivered services, whilst disabled people are passive recipients with little, if any, opportunity to exercise control” (p.103).

Within HE there are a number of policies and directives which are aimed at levelling the playing field and promoting participation. Introduced in the Higher Education and Research Bill (2016/2017) is a requirement that HE institutions

ensure they offer positive outcomes for disadvantaged students by demonstrating a commitment to widening participation and fair access (Business, Innovation and Skills, 2016). Ensuring HE is accessible to all is posited as promoting opportunities for disadvantaged learners as well as developing reputational excellence and financial reward for the institution (ibid). Policy approaches that attempt to offer solutions, such as for the improvement of chance for disadvantaged learners, may be hard to assess in terms of successful implementation without understanding what it is students envisage and experience as barriers to participation. Thus, there is a possibility that policy aims remain rhetorical rather than developing as action.

In addition, that institutions are attempting to manage financial constraints in a difficult economic climate and are subjected to massive changes can also mean policies remain abstract rather than concrete, as does the need for universities to provide reasonable adjustments without additional resources. The outcome may be that, potentially, students are in danger of being viewed as financial assets or risks, either worth competing over or disregarded. If universities are facing increased pressure to bring in students as a means of increasing financial reward the implications for disabled students could be greater than for previous generations, simply as they may be considered more expensive, or riskier, investments.

However, taking a Freirean stance towards the purposes of education, whereby education is understood as a key component of enacting social justice, universities would appear to offer a unique opportunity where students are able to achieve both intellectual and physical freedom, something which Freire (2006, p.47) contends is “the indispensable condition for the quest for human completion”. This could be seen as reflected in the growth of academic interest in disability in the 1990s and into the early 2000s and in the engagement with disability across a number of disciplinary fields. This again suggests that there are several ethos’ at

play in HE. This growth of interest is argued by Barnes (2007, p.135) to be “inextricably linked to the politicization of disability studies”. Locating the discipline as a means of knowledge production around the experiences of disabled people within academic disciplines would suggest an inherent interest in the ways in which disability is represented within higher education. However, whilst discussing the ways in which the academy develops relationships with disabled people and disabled groups and the management of this within the increasing demands on the production of academic knowledge, Barnes (2007, p.143) suggests “we are in constant danger of justifying that which we seek to critique”.

Barnes’ suggestion resonates when considering the ways in which disability is positioned within higher education and the ways in which disabled students, and particularly visually impaired students, remain on the fringes of participation. Barnes (2007) further contends that having expanded, the space within the academic arena to engage with disability and Disability Studies is becoming increasingly limited, yet the importance of maintaining and ultimately developing the involvement of disabled people within academia is vital to challenging disabling structures and attitudes.

### **Higher education and the hierarchy of impairment**

In Barnes’ (2007) analysis of who attends universities he concluded that there was a prevalence of middle class, non-ethnically diverse, disabled students. Barnes also highlights an interesting juxtaposition that draws heavily on perceived measures of class and the value attributed to certain types of disabled people. Similarly, Deal (2003) has noted a hierarchy of impairment which identifies that certain impairments are less accepted and valued by both non-disabled people looking from the outside in, and by disabled people examining their own and other’s positions within the disabled community.

In more recent research Beauchamp-Pryor (2011) in her work with disabled students within a Welsh HEI notes the ways in which disabled students perceive a hierarchy of impairment and use this to position themselves amongst other disabled students. Whilst such research may make for uncomfortable reading it is vital in helping to understand the experience of being a disabled student. This builds on the understandings established in the earlier research in several ways, but it must be emphasized that little other research exists which examines the ways in which disabled students form their identities in relation to the value of their own impairments.

As a visually impaired student Beauchamp-Pryor was uniquely positioned to examine the ways in which other disabled students placed importance upon the ways in which they were identified. However, whilst she notes that students welcomed the opportunity to share stories about their experiences, the research indicated that a shared experience could not presume a collective outlook. Beauchamp-Pryor usefully focuses on the importance of the shared experience of oppression as a means to develop a collective understanding of the experience of being disabled and also calls for an understanding of the multiplicity of factors that are experienced such as gender, race, age, religion to fully grasp the experience of inequality and exclusion. Similarly, Shakespeare (1996) had urged caution in relation to engaging solely with an identity of disabled, arguing that to do so ignores the multiple other identities which are at play, stating that recognising multiple identities rejects the enforced homogenization of disabled people. In making this assertion, he invited examination more widely of the individual experience of disability and impairment.

Discussing the ways in which normalcy as a concept is played out and is recognisable within the participation of disabled students generally in higher

education, Madriaga et al (2011, p.901) note that such thinking around normalcy replicates the notions of non-traditional students as “non-white, working class and/or disabled”. This conceptualises difference as disadvantage, othering those contained within its parameters; predominantly those students traditionally grouped together in terms of disability, ethnicity and educational background on the basis of their non-normative characteristics.

This body of literature highlights the importance of taking an intersectional approach to examine the intersections of difference and how these are constructed as disadvantage. Intersectionality can be defined, as Hill Collins and Bilge (2016, p.2) describe it, as, “When it comes to social inequality, people’s lives and the organisation of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other”. They go on to add that, further, ‘Intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves’ (Hill Collins and Bilge, 2016, p.2). Shakespeare and Beauchamp-Pryor also recognise and articulate this complexity in thinking about multiple identities, and this research extends it further in relation to HE.

### **Disabled students in HE**

Research which examines the experiences of disabled students generally, and thus may include visually impaired students, is widespread (Baron, Phillips and Stalker, 1996; Borland and James, 1999; Holloway, 2001; Fuller, Bradley and Healey, 2004; Riddell, Tinklin and Wilson, 2004; Shelvin, Kenny and McNeela, 2004; Fuller *et al*, 2006; Jacklin *et al*, 2009; Vickerman and Blundell, 2010; Jacklin, 2011; Redpath *et al*, 2013). However, these instances do not address the experiences of visually impaired students directly, instead often drawing upon a multiplicity of impairments under the banner of the disabled student experience. Consequently,

they are not engaged with the complexities associated with individual and specific impairment related experiences (Madriaga and Goodley, 2008).

As Barnes (2007) notes, the reliance on the Social model as a means to examine the experience of being disabled generally has led to a lack of exploration about individual experiences. This may be due to the conceptualisation of disability as a social and structural barrier affecting a significant section of society, and as such, this homogenization is imperative as a collective challenge to such barriers. However, this leads to the removal of individual and autonomous action and challenge from individual impairment types, who likely experience the phenomena of being disabled differently as a result of their impairment.

By constructing impairment as difference and as a result creating a binary of disabled and non-disabled students the significant research in this area is unable to illuminate a position beyond a generalised discussion of the experiences of disabled students. However, this wider evidence base is needed in locating this research. Whilst the literature reviewed in terms of the experiences of disabled students is undeniably useful as a tool for drawing out general and wider discussions around being a disabled student, there is a distinct gap within the literature this study aims to partially address.

### **Studies of specific impairment 'groups' in HE**

Madriaga and Goodley (2008, p.116) conclude that examining the experience of a specific impairment 'group', "recognises the divergent ways in which different impairments are constructed and responded to in educational settings". This moves away from focusing more on a general understanding of the experiences of disabled students and suggests the potential and importance of understanding individualised experience as a way of promoting a collective challenge. As Mark Sherry (2016, p.7) helpfully contends:

The challenge is to develop a complex and nuanced approach which neither lumps all impairment together *a priori* nor ignores similarities in the cultural construction of impairment and disability as collective experience.

Similarly, Madriaga and Goodley (2008, p.116) assert that moving away from reaffirming the “neutral significance of specific impairments and conditions”, research should instead “recognise ... (specific) impairments as having (particular) socio-political and epistemological foundations” (Ibid), thus challenging an enforced homogenisation of disabled students. Their examination of the experience of Asperger’s within higher education, they suggest, highlights the need for a recognition of “the divergent ways in which different impairments are constructed and responded to in educational settings” (Ibid). Whilst neither specifically discuss the experiences of visually impaired students, both assert the need for a deeper and broader approach that can examine the constructions of impairment both in terms of understanding individual experience without removing the strengths associated with sharing collectivized experience.

Extending his argument, Sherry (2016) discusses the need for a development of a sociology of impairment rooted in an intersectional approach that examines race, class, gender and sexuality as a means with which to understand the experiences of impairment, particularly about the cultural constructions attached to impairment types. He suggests that, “culture is the key to understanding how individuals and communities make sense of certain physical, sensory, cognitive, intellectual or mental experiences” (Sherry, 2016, p.7). By doing so, he argues, the power that is embedded within the wider discourses around impairment can be uncovered. This means that a body of research about conceptual frameworks regarding impairments points out the importance of work on individuals and specific impairments, as a way of adding to collective discourses about disability.



## **The visually impaired student experience.**

As noted, little literature solely examines the experiences of visually impaired students. For instance, whilst Beauchamp-Pryor (2011) incorporated her own experiences into her research, that was not her main focus. The research that does exist that specifically addresses this experience takes a range of approaches, with their breadth and scarcity indicating the potential of this area for additional research. For instance, there may be a focus on a single institution, as is the case with Bishop and Rhind (2011) whose use of interview and engagement with students' prior learning experiences in exploring barriers and enablers in a single institution is similar to my approach. However, their focus on a single institution means that discussion of, for instance, accessibility, is necessarily specific to location and so conditions and experiences might not be replicated elsewhere. All the same, their emphasis on the student voice, albeit within a more directive interview framework than I employ, begins to reveal distinct and individual accounts in a way I build on here.

There is also work on how particular disciplines may be made more accessible, such as that by Frank, McLinden and Douglas (2014) on physiotherapy and even research on the relationship between the built environment and the body, as Lourens and Swartz (2016) explore. These fine-grained studies explore emotional and psychological aspects of experience, again something that I also contribute to through the discussions with the research participants.

Another area is analysis of the impact of visual impairment upon study in comparison to non-disabled peers as shown in the account of Richardson and Roy (2002). This research drew conclusions about the impact of visual impairment on academic achievement. It is this work that Bishop and Rhind (2011) sought to develop further having concluded that more could be done by institutions to support

students. They also built on research addressing the experience of disabled students more widely that emerged in the late 1990s which specifically analysed different kinds of barriers, such as that by Cole-Hamilton and Vale (2000); Owen-Hutchinson, Atkinson and Orpwood (1998); Tinklin and Hall (1999) and Simkiss, Garner and Dryden (1998). However, where Bishop and Rhind (2011) differ is in their inclusion of positive accounts, so expanding the narrative about identity and experience whilst still acknowledging obstacles to study.

### **The ideal student and policies of participation**

Whilst the ideal student can be epitomised in many ways, applying the concept of the ideal citizen to students in higher education illuminates the ways in which the corporeal standard student is epitomised as the ideal student. This is even suggested by analysis of some of the policies and directives developed to address the low numbers of disabled students currently in higher education, such as the 2017 Disabled Students Sector Leadership Group (DSSLG) report “Inclusive Teaching and Learning in Higher Education as a route to Excellence”. This encourages universities to make provision and reasonable adjustment for the needs of disabled students and was posited by Jo Johnson, then Minister of State for Universities, Science, Research and Innovation as supporting the Government’s social mobility agenda.

The underlying refrain within this report is the need for universities to manage the reasonable adjustment requirements needed for disabled students in a way that broadly supports the agenda of improving outcomes for students, but it also focuses heavily on the organisational benefits to the HEI. Whilst the report notes that disabled students are significantly underrepresented within higher education it tends to emphasise the risks and benefits for the university over and above the needs of a diverse student population. This report offers a narrative about

institutions, and what is best for them, not disabled students, something emphasised in the way that failing to create an inclusive teaching and learning environment is discussed in terms of potentially having a negative impact on the reputation and national student survey scores of individual institutions. This can be read as offering a carrot and a stick, in the form of enhanced or injured reputation, to encourage institutional engagement, but doing so removes any emphasis on the disabled student. What hovers behind the report is a narrative that institutions favour the ideal student and need coercion, or encouragement, to address any others.

The ideal student is also fully in line with neoliberal philosophy in terms of outcomes. Kelly, Fair and Evans (2017, p.3), through their examination of the representation of the student in higher education suggests that “policy in the UK increasingly conceives undergraduate students as individual entrepreneurs, transacting their way through higher education, preparing themselves for high-earning success in the global field of market competition”, a depiction which again shows the importance that is placed on the student negotiating their academic career in order to seek out the most financially rewarding and economically worthwhile roles upon completion. Referring back to Goodley’s (2014) discussion about the construction of the valued citizen as one who is autonomous and self-sufficient, it appears that higher education replicates these values. To be the ideal student is to leave higher education as an economically viable unit, autonomous, self-sufficient, ‘normal’ and reasonable.

An ideal student, then, is one who requires little or no specific intervention and is cheap in terms of their needs, and so will pose fewer challenges for an institution, which may imply a preference for non-disabled students in a competitive market. This may seem somewhat unlikely as many legislative processes are in place to challenge such practices, yet, there remains an underlying narrative that

higher education may not be a viable option for disabled people, or that their participation may amount to institutions taking an economic risk. It is interesting, for instance, that all participants within the DSSLG (2017) strategy group were academics or in management within universities and that there was seemingly little involvement of disabled students as either stakeholders or as part of the underlying research that the report is built around. Thus, the ideal student appears as an externally produced construction, in this report and elsewhere, functioning as a binary to the disabled student, who requires solutions derived by others in order to participate in higher education in ways similar to their non-disabled counterparts.

### **The pathologised student identity and the DSA**

The study by HEFCE (2017) which examined provision for disabled students across the higher education sector summarised that current provision for disabled students is inconsistent across the sector, with a general self-assessment by all providers creating a six out of ten score in relation to the progress towards a social model of disability as a model for provision. The report “Models of support for students with disabilities”, employs terminology which draws heavily on person first language and which is often positioned within social model thinking as focusing on an individualistic model of disability, placing the ‘fault’ of being impaired with the individual. However, the content and even the title is perhaps unsurprising given that the report itself notes that many providers still retain a medicalised notion of disability (HEFCE, 2017, p1).

What this report reflects is that from the very outset of the process of going to university students who identify as disabled are positioned within a discourse that pathologises their student identity. Students who need access to specific learning aids and resources, or who require a sighted guide or mobility support around the campus, to and from lectures or need support to access the library, for example, are

required to complete provide medical confirmation of their disability. Medical professionals are required to comment on impairment and its effects. This forms the basis of a student's Disabled Students Allowance (DSA) application that provides funds to pay for material and personalised support. This means that students are positioned as different and other from the start of their application, which in turn can unconsciously cement a feeling of 'other' in the individual and the institution.

Whilst it could be suggested that students have a 'choice' about whether they seek recourse from DSA to access support whilst at university, for many students it is necessity. In effect, they must come out as disabled and so actually have no choice as to whether to reveal themselves or not. Instead, they are forced into a position of being recognised as disabled by the necessity of seeking support. To do this they need to act autonomously and within reason (Goodley, 2014) in order to fulfil the expectations held about the valued citizen and to take their place within the place and space that is created for disability. If they do not, particularly within the conflicting demands that are placed on disabled people to accept the rehabilitative and expert knowledges which present ways for disabled people to act like non-disabled people and thus be accepted within the culture they are attempting to access then they run the risk of exclusion. Here the double binds (Titchkosky, 2003), the expectations around disability, force conformity to societal expectations, whilst positioning the disabled person as different. This can be seen as highlighting the inherently ableist nature of the environment that they are seeking to be part of.

The HEFCE (2017) report notes that there is a medicalised model of disability within the DSA process and that this influences the ways in which people are required to disclose a disability. However, they go no further than to emphasise that this is in tension with engagement with a social model of disability. Universities, then, may claim to adhere to the social model, but the foundational documentation

required to access support is entirely medicalised. The report offers no steps or process to change or challenge this. Arguably the centrality of the DSA within a neoliberalist higher education agenda means that disabled students “who are not capable of existing without such support mechanisms risk being cast out by neoliberalism and hounded by ableism” (Goodley, 2014, p.29) and so disabled students are forced to accept a pathologized student identity in order to gain access to higher education.

### **Higher education, employability and the VI student**

As noted earlier in this thesis, the monetisation and marketization of the sector and the ubiquitous assumption that higher education is the gateway to increased financial reward and status within society have located the university as business rather than social enterprise. Further, it is often assumed to be the benchmark for accessing opportunities for well-paid employment. However, there is also a narrative that, for employers, there are not enough graduates of the type they require. In the report “Solving Future Skills Challenges” published by Universities UK (2018), they state that “In 2016, 440,000 new professional jobs were created, yet there were only 316,690 first-degree UK-based graduates, leaving a recruitment gap of 123,310, more than double the gap in 2015” (accessed 20/8/18). The report goes on to detail how in the future greater levels of professional and technical knowledge will be required, arguing that the workforce will require a commitment to lifelong learning, and that as a result there will be a dissolution of linear careers paths. The report notes the need for diversification in the types and modes of provision and delivery within the HE sector and recommends that the links between employers and providers is strengthened creating more opportunities to engage with employment as part of a student’s academic career. What this suggests is that there is an increasing correlation between higher education, employers and employability.

The positioning of higher education in this way is unsympathetic to the alternative paths that people may choose to take in their lives. It is also absorbed by creating a flexible workforce where the individual is held to account for personal 'failures' to keep up to date, rather than placing any onus on employers for training and supporting staff. Upskilling is typically a constant policy aim within such initiatives as "AimHigher" and the current HEFCE guided project "FutureMe" and the development of Degree Apprenticeships and two-year degree offers adds to this drive. Whilst such ideologically driven initiatives can be seen as positive steps towards levelling the educational playing field, there are side effects that may do the opposite. With the assumption that higher education is now more accessible increasing pressure is placed upon young people and adult returners to consider HE regardless of their personal expectations or academic suitability. As financial reward is positioned as an outcome of achievement within HE it is hard to challenge the assumption that participation in higher education should be the goal for any learner.

For visually impaired students who face many structural and societal barriers to participation in HE, and later to the workplace, these alternative routes through HE may simply compound pre-existing issues and, more generally, increase the disparity between disabled and non-disabled students. Visually impaired students, for example, may require support to access many areas of day to day student life, such as texts within the library, or require a longer time to write assignments. Others may require more time, in comparison to other students, to access the information within their course literature, such as module or programme guides, or to carry out practical assessments. This is not only a potential issue with the integration of the proposed new routes to a degree qualification but can also be problematic within current routes.

For visually impaired and other students that are under-represented in higher education, there are multiple challenges in engaging with work experience, and with the graduate labour market. Visually impaired people are less likely to enter the workforce through the graduate level, technical and professional roles that are being posited as the product of the changes in the types of work available in the future. The RNIB suggest that the numbers of visually impaired people in work are decreasing, with one in four visually impaired people of working age in employment. For those who are registered as completely blind, they suggest that this figure is exponentially lower with only one in ten being in employment (RNIB, 2017b). This suggests that employment opportunities are significantly harder to access for visually impaired people, and as employers' needs become a more dominant discourse in HE and it is considered increasingly simply as a precursor for employment, then it too becomes less accessible.

### **Access, higher education and visual impairment**

In this section I flag up research on access. Again, due to the limited research specifically in relation to the experience of visual impairment I largely draw on literature that examines access regarding disabled students more generally. This was also the case in the only comparative research to this thesis, the small case study by Bishop and Rhind (2011) who employed the Owen-Hutchinson et al (1998) categories of barriers, these being attitudinal, institutional, environmental, and physical. In contrast, I begin with Tinklin and Hall (1999) who proposed five barriers to education for disabled students: physical environment, access to information, entrance to higher education, assumptions of normalcy and levels of awareness. In drawing this together with Michalko's (2002) research, I demonstrate how a generalised model can be reconstituted in relation to a specific impairment.



Access takes many forms, as these models suggest, such as physical access to an environment or being able to participate in activities and experiences. For Michalko (2002, p.141) our environments are constructed “both literally and figuratively – on the basis of seeing, hearing and walking” and for those whose identities are constructed around being without these attributes’ environments can be exclusionary. This brings together three of the barriers mentioned by Tinklin and Hall, the physical, assumptions of normalcy and levels of awareness. Drawing further on Michalko’s reasoning about the ways in which disability identity is a distinct catalyst in accessing the environment, he suggests (Michalko, 2002, p.141) that the demand for accommodations that would make the environment accessible as a right to all participants in a society, and particularly disabled people, is:

[b]ased on an image of disability that goes beyond the individual. It brings the physical and social environment, cultural portrayals of the body, and collective representations of normalcy and abnormalcy together in a gestalt that collectively works to generate the phenomenon of disability.

Therefore, access is restricted by representation and cultural, societal and physical assumptions about disability. Any adaptations to environments are thus likely to challenge ingrained assumptions of ableness and value associated with normalcy, making a lack of awareness significant. Environmental factors such as access to buildings or engaging with signage, a form of information, are built around an assumption of normalcy as commonplace. It is this assumption that makes inaccessibility prevalent and it is against this prevalence that visually impaired students are positioned.

Inaccessibility, Michalko (2002, p.55) further contends, “is ‘seen’ by society as a ‘natural mistake’ at best and a ‘natural necessity’ at worst”. Further, Oliver and Barnes (2012) suggest that the ways in which disability and impairment are constructed is based on an unspoken claim that humans are adaptable, whereas

the physical environment is not. They contend that this “flies in the face of reality since historically humans have moulded the environment to suit their needs rather than the other way round” (2012, p.19).

For visually impaired people the concept of accessibility is far more than just about adaptations to physical barriers such as steps or inaccessible signage, although this tends to be the narrative that dominates, perhaps via the Social Model. As Oliver and Barnes (2012) suggest, there is an ideology in action that actively works against adapting environments. When visual impairment is repeatedly constructed as in deficit, or feared for the connotations associated with it, then these barriers are far more ideological than tangible.

The arguments about environments noted here can be applied to aspects of university, although they cannot address entrance to higher education directly, and access to information in the context of HE goes beyond signage. Access to information takes many forms, but some are based on interaction with lecturers, support workers and other staff, and so issues around awareness and assumptions of normalcy may come to the fore. Of course, access in relation to taking part in activities is hugely significant for HE where degrees are based on participation in lectures and seminars amongst other activities.

Regarding lecturers, van Jaarsveldt & Ndeya-Ndereya (2015) examined, in a study in a South African university, the ways in which lecturers’ distance themselves from disabled students and the effect this has on inclusive learning environments. They discuss the ways in which lecturers have little experience and expectation in relation to the involvement of disabled students within the learning environment, a barrier to access created by lack of awareness. Furthermore, they note that disabled students are often positioned within a “them and us” dichotomy which others disabled students and excludes them from the learning environment. Similarly, in

Holloway's (2001) study of a specific institution the participants noted a difficulty whereby individual departments developed piecemeal responses to disabled students' participation, resulting in lack of continuity for those students. She notes that these individualised responses to disabled students can be understood as a response from individual staff regarding the ways in which disability itself is perceived within the university (Holloway, 2001).

Barriers to access regarding awareness were also created due to a fear of causing offence, which stifled interaction, and limited students' access to the educational experience in Van Jaarsveldt and Ndeya-Ndereya's (2015) research. They note that staff expressed fear of saying something which could be construed negatively towards visually impaired students such as referring to seeing them later or asking if they had seen a particular aspect of the lesson. Consequently, Van Jaarsveldt and Ndeya-Ndereya (2015, p.10) suggest is language laden with exclusion and thus "educational practice within this context is informed by one's theoretical approach to disability. Support of the medical model of disability, for example, leads to the special education approach". Whilst this research is not within a UK HEI it shows how ingrained assumptions about disability impact upon the ways in which disabled students are treated, encouraged and enabled to participate. Assumptions that remain inherent also create barriers that are more than physical.

An understanding of access and visual impairment directly relevant to this thesis is offered by Beauchamp-Pryor (2011) who writes from the perspective of a visually impaired person. What makes this account distinctive is that Beauchamp-Pryor, after a surgery she describes as successful, is no longer visually impaired in the traditional medicalised sense, something which allows her to discuss the ways in which she is expected to conform to the behaviour of a sighted world, despite having spent the majority of her life as a visually impaired person. This unique

standpoint highlights the ways in which the expectations of the normalised position of being sighted are imposed upon people and the ways in which by not meeting this expectation visually impaired people are perceived differently. The assumptions about what constitutes normalcy and their basis within having sight form a distinct barrier that underpins the experiences of visually impaired students in higher education.

In the case of Redpath et al (2013), who carried out research into the transitions of disabled students from statutory education to higher education in Northern Ireland, accessing information was identified as forming a barrier to participation pre-transition and in HE. Whilst earlier in this chapter information was described as physical, or about degree content, in the context of this research it is about support and so directly related to access in the sense of the capacity of a potential student to enter HE. For example, participants in their research were unaware of the types of support they could and would receive.

Once in university, access may be limited through the ways in which disabled students are able to access the teaching and learning resources. This is significantly different across each provider with little standardisation across the overall sector. The research of Vickerman and Blundell (2010) and Fuller et al (2004) highlights accessibility of learning and teaching resources and systems within HEIs. Vickerman and Blundell (2010) note that students within their study emphasised that there was a lack of discussion with disabled students about their needs in relation to their perceived and real barriers to learning and assessment. Holloway (2001) adds to this by discussing the additional costs associated with being a disabled student, in relation to the equipment participants within her research required to access course materials in the same way as other, non-disabled students. She noted that in many cases, whilst DSA can meet the costs of certain equipment,

students were required to fund additional equipment individually or to seek funding from external sources. This is not to say that non-disabled students do not need to fund resources, but to insist that this forms an additional practical, temporal and financial barrier for disabled students.

Holloway (2001) notes that there is a temporal element to barriers regarding access given that time is needed to arrange, for instance, exam support or additional time to complete tasks. It is often a necessity that time is needed to meet with support workers to access the library or written information required for their course. This created additional stress for these students, Holloway (2001) contends, and anxiety about time was a recurring theme for her participants. Holloway highlights here the importance of carrying out research with disabled students to understand the daily negotiations that they undertake to access and maintain their participation within higher education.

Borland and James (1999) address a specific barrier to access, that of initial engagement with HE. They note that issues are present from the start of a students' experience, suggesting that communication between parts of a university can be problematic and lead to a breakdown in communication about the types of support that each student might need from different departments. For example, communication between disability departments and personal or course tutors may not occur, or the information shared within this communication may not be fully appropriate in ensuring provision is accessible. This is not solely an issue relating to disabled students, so it is perhaps more appropriate to suggest that making sure information is fully accessible will improve the participation of all students regardless of learning styles or needs. However, for disabled students the process of informing their institution about their impairment may increase an expectation that suitable provision will be in place from the outset. As Borland and James (1999) note,

students felt that by disclosing the relevant information to the university in their application it would be disseminated to relevant departments. They state that students were “quite mystified by the fact their school did not appear to know about them... in other cases it raised questions in the student’s mind about their value to the institution” (Borland and James, 1999, p.90).

Tinklin and Hall (1999) argue that how students perceived their experiences in HE was largely dependent on the level of awareness of staff members they were engaged with. Positive experiences were generated by well-informed staff, something they suggest came from the individual staff members own experiences of or interest in disability. Negative experiences arose from staff being unaware of how to engage with disabled students or “operating on assumptions about a student’s needs without checking with the student concerned” (Tinklin and Hall, 1999, p.191).

Alongside the barriers potentially created by attitudes and assumptions held by staff within HEI’s, another barrier may be the expectations and beliefs about being a student held by other students. Tinklin and Hall (1999) contend that attitudes towards disabled students held by other members of the student cohort can have a major impact on the disabled students’ enjoyment, motivation and ultimately their participation. Alongside the disclosure of an impairment to the services within the university, students are required to negotiate disclosures to their peers and student cohort. Many of the issues that arise at the point of disclosure, such as stigma or negative assumptions about disability, are likely to be existent in the negotiation of creating their own student identity. Borland and James (1999), for example, report that some students found other students within their cohort were supportive and would provide practical assistance with locating resources or catching up with examination preparation. However, the same study reported that these initial

friendships could develop into negative relationships if disabled students began to achieve good or better marks than their peers.

Additionally, the research flagged up that informal support networks in universities could promote positive experiences for students. This included relationships with academic or support staff who would offer unofficial support or assist with queries in an appropriate way. Such support was seen as beneficial to their participation as it broke down barriers without going through more formal and bureaucratic processes.

A final set of barriers to access is identified by Tinklin and Hall (1999, p.193) who argued that at the time of their study disabled students were being “offered a model of assisted access to a system which inherently includes obstacles to their participation”, something which arguably remains in place today. One example is the provision of support workers and services for disabled students. Whilst universities currently have to provide support for disabled students under equalities legislation, there appears to be disparity in the ways in which this support is offered, given that how support is actually delivered is dependent on the institution (HEFCE, 2017). Support is often provided to disabled students via an amalgamated provision within the university, such as the disability support team, or in some instances specific departments, such as a sensory support team who work with certain impairments.

Disparities highlight the convoluted and contradictory ways that disability is constructed within HEIs, as noted within the HEFCE (2017) report. This stated that not all university providers offer a standardised ‘triage’ based student support system, with many having individual departments, a more traditional format. For visually impaired students accessing support services on an ad-hoc basis may not be suitable. Additionally, physical and environmental constraints may deter or

prohibit visually impaired students from contacting and accessing support staff in this way.

In addition, there may be barrier in terms of consistency of support for students in a triage system of support services. Some may not feel comfortable with the possibility of encountering a different member of staff on every visit and so being required to divulge personal information to a new person each time. Despite this, the HEFCE report notes that this approach “enables institutions to triage and signpost effectively and to provide joined-up services, and with the move to inclusive provision there appear to be close links and blurring of boundaries between learner support and disability services” (HEFCE, 2017, p.47). This appears to enable higher education systems improve inclusive practices; however, it is questionable as to whether this top-down approach is in the best interests of the student population. Whether a standardised system is suitable to the broad range of students’ requirements is largely unexplored and it may have a homogenising effect.

## **Conclusion**

In locating this thesis in relation to existing literature in the field, the chapter shows that there are few directly comparable studies in terms of focus on a specific group, and indeed, there are few studies at all on the experience of visually impaired students. Consequently, the thesis is placed alongside work that addresses a wider experience of disability and HE, acknowledging that this typically does not address specific concerns and issues. The literature review makes it clear that there are a number of factors that impact upon the experiences of disabled students within higher education, including various constructions of the student on the part of institutions, support services, peers and the student themselves. These may be seen as constructing the disabled student as other in relation to a neoliberal ideal student.



In addition, the academic studies this chapter identifies a constant engagement with, and critique of, policies and practices in HE, as noted in the chapter, that have created barriers, despite being intended to demolish them. It is clear that lack of student voice within the development of policy and practices creates a top-down approach. Some of the research identified begins to address that through the collection and analysis of interviews with students about their experiences. This is still, generally, in a context of addressing the experience of being a disabled student rather than through research focused on specific impairments and the student experience. This may be considered to reflect how Disability Studies has developed as a discipline and the core theoretical concepts and models that inform it.

The top-down model that the chapter indicates dominates HE relies heavily on input from non-disabled professionals and providers within the sector, as the policy and other professional reports indicate. Consequently, these reports cannot present a challenge to the disabling barriers present within higher education. Without directly understanding what disabled student's experience, and in particular, visually impaired students, barriers to access of various kinds will remain. These issues are shown in the academic literature focusing on access of various kinds, again particularly in the work of those academics who focus on the student voice.

The literature in the field indicates that the involvement of disabled students within higher education replicates the ways in which disability is consistently constructed and positioned on the fringes of society. As the marketisation of higher education as a means to improve financial standing and reward continues, visually impaired students run the risk of being left behind should the value of visual impairment be positioned in negative terms. As is shown elsewhere in this thesis

how visual impairment is constructed is rooted within a hegemonic discourse of power and normalcy.

### **Chapter Three: Research Methodology and Methods**

This chapter examines the methodological approach and the methods used within this study, which led to the emergence of the findings and discussion found in the final chapters. This chapter examines how the research methodology and related methods have developed and what this has meant to the practicalities of the research process and project. The research draws upon Grounded Theory (GT) and upon Social Constructionism to examine the social worlds that the research participants inhabit. Alongside this runs an examination of the importance of carrying out research that aims to emancipate the experiences of disabled people in contrast to traditional methods that have positioned disabled people negatively within a framework of repressive research, 'done to' rather than 'constructed together'.

Thus, this chapter examines the why, the how and the what of the research – why the research takes an emancipatory stance; why the methodologies used were chosen and the how and what of the research carried out. I discuss here the underpinning ethos to the research and why the research was carried out in this particular way. I also briefly explore the impact of historical research upon disabled people to explain and demonstrate the importance of a stance that seeks to challenge oppressive and discriminatory research practices and values. By doing so I show how the research framework developed and how this led to the development of the data collection methods and analysis used. In support of this I have included within the Appendices located at the end of this thesis (pp. 288-290) an example of the documentation sent out to recruit participants and also a semi structured interview schedule.

I discuss key factors that underpin my research with visually impaired people and the importance of these when carrying out disability research more generally. I examine why Grounded Theory became significant to the research project and show

my consideration of the applicability of other methods to the study. Following this I explore the ethical considerations important to the research project and those associated with disability research generally. I then discuss the study design, exploring the data collection methods used. Finally, I discuss the importance of taking a stance towards research that incorporates and strengthens the position of disabled people as active participants within the research process.

### **An overview**

I begin by discussing the qualitative stance taken towards this research and explain why this was appropriate to the type of research undertaken. As noted previously, the research takes a Critical Disability Studies (CDS) approach to the exploration of tensions between being visually impaired, a visually impaired student, and HE. I do not take a deductive bearing that presupposes theory and as such would assume from the outset what these tensions may be, indeed, as suggested at the start of the thesis, they may be constructive rather than oppressive. Rather, I worked from the basis that visually impaired students' experience is not a fixed and rigid set of disabling practices bounded within a single time and space but a conglomeration of individual experiences within a multitude of ableist and normative constructions. To measure these within an arbitrary categorisation would presume expert and insider knowledge held by the researcher over and above the expert position of being a visually impaired student and a visually impaired person.

In terms of how this has shaped the research, it became clear that without the involvement of visually impaired people in the research there was much that would be excluded. Drawing on Goodley and Moore (2000, p.826) my position as researcher is "firmly on the side of disabled people". Whilst, to this end, a Participatory Action Research project would have been highly suitable the constraints associated with the geographic spread of participants was likely to cause

many issues before the project could even begin. It was, all the same, crucial that visually impaired students were included in shaping the way that this research took place, something I explore in more depth later in this chapter.

Therefore, I set out here my position towards the means by which I explore experience and not the importance of a 'phenomenological sensitivity', (van Manen 2007, p. 2). Rooted within interpretivism hermeneutic phenomenology seeks to clarify interpretation. Similarly, to the social constructionist aspects discussed within this thesis and the importance of this to the research, a sensitivity to a hermeneutic approach is important to help uncover the ways in which both participants and I uncover the ways in which experience is contrived. So, whilst it is vital to explore the milieu of understanding which constructs reality (Gadamer, 1975) hermeneutic phenomenology asserts meaning is produced not reproduced and thus where I draw upon 'lived experience' of the participants I use this as a way to give meaning to the stories that participants share about their lives and how these are constructed whilst recognising my own constructions and understandings.

This research straddles education and CDS and therefore the case study approach was considered however the research is firmly rooted in CDS and thus rendered a case study approach as heavily nuanced with medicalised discourses often experienced by disabled people. This is based on the wording that the case study employs and infers. Case Study approaches are often significantly related to single instances and cases within medicalised approaches to disability and this therefore reduced the experiences to a dichotomy which is often negatively used within the lives of disabled people. Where case studies are useful, the wording is not. Thus, this research swerves from labelling the stories and experiences of the participants as case studies.

## **Social Constructionism**

Firstly, I begin by discussing the Social Constructionist roots of this research. Crotty (1998) suggests that Social Constructionism is an epistemological perspective that takes a position whereby the realities encountered are constructed through interactions with others, and as Berger and Luckmann (1966) contend, meaning is made through shared understandings of these interactions. Andrews (2012) suggests Social Constructionism shares common underpinning philosophical roots with interpretivism, in so much as that they both examine the construction of people's lived experiences. However, Andrews (2012) contends that this is where the similarity ends, as social constructionism examines the subjective nature of reality as opposed to an objective truth which he suggests lies innately within traditional interpretivism. Objectivism suggests there is a reality that exists as an external fact beyond the realms of what social actors, can change or influence. These realities, such as cultures or organisations, possess and provide a discourse, rules and categories that are tangible and apply pressure to ensure conformity to their norms and requirements. As part of a culture or organisation actors are unable to alter these realities (Bryman, 2008). I am uncomfortable with this approach as I feel it does not allow for the importance of the individual and the choices they make or have.

Constructionism offers an alternative perspective, which challenges the presupposed fixed reality associated with objectivism, suggesting instead that reality is defined and constructed by those who live within a society and is therefore subject to change. Subjectivity has been critiqued as an approach that ignores the facts and truths that objectivism sees as existing and is thus considered weaker than objectivity. However, as Becker (1982) contends, no one set of rules or understandings is appropriate as a solution to all situations. We are required to

negotiate understanding and develop bespoke or alternative responses that help us to answer questions, solve problems and navigate the worlds.

Berger and Luckmann (1966) note that what we know is created by those with knowledge, who become perceived as holding an expert position. Within the constraints of this expert position, knowledge becomes that which is given credence, is initiated into patterns and translated eventually into what is seen as objective knowledge, becoming a base upon which future generations can draw, perhaps as what might be thought of as a common-sense worldview. The issue with such thinking is that by basing what we know on traditional notions of a reality the connotations implied by this 'knowledge' may be problematic. For this research, for example, the traditionally negative connotations around visual impairment and blindness are particularly significant. Burr (2005, pp.3-4) notes that we engage with certain specifics when we understand our worlds. These specifics are categories that are historically and culturally particular to, and products of, the prevailing social and economic arrangements of the time. Social constructionism, she contends, invites us to be critical of assumptions that position knowledge of the world as unproblematic and revealed to us through objective value free observations. Instead, classifications and categories provide us with divisions and divides, especially binary ones, which may be seen as common sense to an extent – for example male/female; disabled/non-disabled; yet when these are examined, these binaries are revealed as located historically, socially and culturally and as such can be examined through lenses which incorporate these categories.

To be visually impaired or blind in relation to expert knowledge or through historical conceptions of disability and sight loss may provide an understanding that does not allow for the individual experience beyond the positivity associated with strongly and positively identifying as visually impaired, blind or disabled, or one that

constructs visual impairment solely in terms of deficit. Visually impaired people, in this model of expert knowledge, may be seen as unable to conform to the objective realities of a society or culture in the ways that are expected through the common-sense approach or repeated patterns that have formed the norms of a culture or organisation nor can they change this worldview as 'outsiders'. Instead, they will remain bounded within a reality that does not allow for change.

In contrast, if disability is to be seen as a social construct – in so much as disability is a status ascribed to those with impairments and who are thus disabled by virtue of their environments and presumably also the time, culture and society they live in (Burr, 2003) then one can engage critically with why and how these positions are constructed and maintained by examining the ways in which these are replicated in interactions.

In relation to visual impairment, a social constructionist perspective affords one an understanding that the overarching knowledge about VI and disability will influence both visually impaired people and non-visually impaired people alike. The meaning that is created is located within existing constructions about VI, which are replayed and reconstructed by both groups and the individuals within them. How perceptions of these categories are constructed is dependent on the interpretations that are already held by the meaning makers and seen within dominant discourses. Hughes (2007) contends that the existing negative ontology of disability, one that is associated with the frailty of human bodies and the positioning of able-bodied and disabled, compounds the notion that human worth is associated with ability. Further, Hughes (2007) argues that in a society built upon a hegemonic discourse such as this the qualities ascribed to being disabled will always remain negative when contrasted with those of able-bodied people.



Here ontological positioning is constructed on a base of negativity and deficit unless it is possible to offer an alternative stance, one that challenges the misconceptions that disability and impairment are the result of body and mind being afflicted and weakened and that disability and impairment are both undesirable and detestable. In order to arrive at such an alternative stance, I turn to the critical ontological position which Hughes (2007, p.683) states can challenge such misconceptions for disability studies as a whole, through a focus on the “pathologies of non-disablement” and how these create and position disability. Engaging with an ontological position which recognises the impact and prevalence of negative constructions of disability and impairment yet immediately presents challenges to them is of importance to this research. By engaging with Hughes’ work, I illuminate the foundations of not only my own ontological position, I also create a starting point from which to examine how others construct theirs. If disability and impairment are viewed negatively it is likely to follow that those who identify as having an impairment or being disabled recognise a position which places them as different or other, whether this is perceived negatively or positively. Engaging with Hughes’ contention that a critical ontology can contest the positioning of able-bodied as valued can help to examine the ways in which this might be experienced and ultimately challenged.

At the beginning of the research process, I explored a large range of possible ontological perspectives of which social construction came to seem most appropriate for the project. As a novice researcher, I had developed what could be seen as an entangled position at the start of my work and whilst I had some understanding of where I wished to locate myself theoretically, I was aware that it would take time to discover how this would be fully developed within the research and how this would apply to the research process. In focusing down, I realised that my own alignment was with an interpretivist stance for this research in order to

illuminate the multifaceted connotations prevalent within the experiences of being visually impaired and so examine the experience of 'being' VI through the lens of Social Constructionism.

### **Grounded Theory and disability research.**

Grounded Theory offered a productive way to investigate the research topic because of the way that it approaches data analysis and knowledge construction. The principles of Grounded Theory mean that it commences with an area of study or interest, rather than with a preconceived theory in mind, allowing theory to emerge as opposed to assembling concepts and delineating these as theory, as argued by Charmaz (2014). Constructing research in this way offers insight, enhances understanding, and can provide a meaningful guide to future action. Theory is derived from and grounded in data systematically gathered and analysed through the research process, thus data collection, analysis and eventual theory are closely affiliated, as Denscombe states (2010). Analysis develops from the interplay between researcher and data, whilst maintaining rigour and creativity. Importantly, as Strauss and Corbin (1998) assert, Grounded Theory incorporates a recognition of a deeper understanding of the data, which is manifested through creative ways of asking questions; creating fittingly termed categories and making comparisons.

Grounded Theory also asks that a researcher be self-reflexive, to be aware of the dangers of making assumptions about what it is that is being researched and the beliefs that a researcher might bring to the research at the outset. As I have previously discussed, my involvement with a visually impaired community through personal and professional means, entails a significant alignment with the experiences visually impaired people share with me and that I experience as part of this community. As Charmaz notes (2008) it is vital that researchers within a grounded theory perspective are able to move between their experiences and

understandings of a topic. Rather than bracket out my own knowledge and experience, and thus negate my insider knowledge about the topic, I draw upon Charmaz's suggestion of reflexivity, whilst also being mindful of what Goodley posits (2011, p.23) when he asks to whom disability studies researchers are accountable. Being mindful of that question helps to underpin the research methodology as one that is politically just regarding the research participants. Doing so also aligns with what Strauss and Corbin (1998) state are the key qualities of Grounded Theory; that it builds rather than tests theory; provides researchers with analytic tools; helps analysts to consider alternative meanings of phenomena; encourages researchers to be systematic and creative simultaneously and helps researchers identify, develop and relate concepts that are the building blocks of theory, all rooted within accountability to the research participants.

Returning to the ontological underpinnings of this research shows that Grounded Theory affords a way to incorporate and encourage the shaping of the research as a process of construction and re-construction between participants and the researcher. This is a crucial element of the underpinning of this research, in that rather than taking an elevated expert stance to the research, participants were involved in shaping how questions around their lives were incorporated and most importantly, what these questions were. This research therefore draws heavily on participatory principles of research with disabled people.

It is paramount to the research process that conscious thought is given to the ways in which these students experience their lives, consistently navigating within social constructions that have been placed upon them by others. This is in line with what Charmaz argued, that being that, "Reality is multiple, processual and constructed- but constructed under certain conditions" (2008, p.402). She suggests that these conditions accept that whilst agency occurs it is often within a "pre-

existing social frame with its constraints of which we may be unaware, and which may not be of our choosing” (Charmaz, 2008, p.409).

Charmaz also states that it is significant within methodology to take into account “the researchers’ positionality, as well of that of the participants” (2008, p.402). I make clear my positionality throughout the thesis, and my insider/outsider knowledge was laid out transparently to participants from the start of their involvement. Having spent many years working within the voluntary sector with visually impaired adults, young people, children and their families, and the personal circumstances of my relationship with my non-sighted partner, mean that I take on more of an insider position. However, as a non-visually impaired person I have an outsider position. Whilst there are many academics and activists that contest that non-disabled researchers should not undertake research with disabled people there are many others that do not (Goodley, 2011, 2014). The process of GT ensured my position and experience was made clear throughout and it served to encourage frank discussions with participants. Indeed, many of the participants who chose to take part in this research indicated they wished to engage with it because of their knowledge about my own position and experiences and so I was not “merely tolerated as an inquisitor” (Finch, 1993, p.167) instead I was understood as demonstrating valid “insider knowledge” (Watts, 2006, p.399)

In this research, “the researcher and researched co-construct the data- data are a product of the research process not simply observed objects of it” (Charmaz, 2008, p.402). Steering away from any generalising of participants as the researched, and rather than the researcher holding the position of power traditionally associated with research ‘done to’ disabled people, this research was designed to ensure that the participants had some power within the process. This is a particularly difficult task in a research relationship like this, where the researcher

is undertaking PhD research, primarily study that facilitates the researcher's own development.

However, what helps to make this possible is that the data is generated and understood in the contexts it has been taken within, rather than as a decontextualized phenomenon. I did not rely on a single interview, but engaged in several with participants, and returned to them to share how I was working with the data after each stage, aiming towards co-construction. This meant there were a number of opportunities for research participants to determine how the research developed. Also, researchers taking a constructionist grounded theory approach, Charmaz (2008, p.403) suggests, take on a central reflexive stance to the research carried out, constructing research directions through scrutiny of the process. Thus, the research process responds to "emergent questions, new insights and further information" (ibid). Rather than take an approach which is prescriptive, and which takes assumptions and assertions at its core, testing experiences and data against this, this research explores experiences which arise from the process and responds reactively to the new insights and directions.

### **Social Constructionism and Grounded Theory together**

Grounded Theory affords a useful means with which to develop theory from data. There are differing viewpoints on how it can be used, but here it is Charmaz's constructivist approach that I employ. The development of Grounded Theory has resulted in the emergence of researchers who engage with that which Charmaz (2008) suggests is a modern perspective which recognises and treats the research process as a social construction in itself and recognises the position of the researcher. As Charmaz (2014, p.14) suggests, "subjectivity is inseparable from social existence" and by engaging with the researcher's subject position we make

explicit that researchers are involved deeply with their research. Consequently, research engages meanings and feelings with analysis.

Engaging with a constructivist approach to GT allows us to address what Charmaz (2008, p.397) suggests is the “complexity of social life” by answering the questions related to what and how and the resulting relationship between these, which leads to the grander “why” questions. A social constructionist approach shows, “the relativity of the researcher’s perspectives, positions, practices and research situation” (Charmaz, 2008, p.398), along with the reflexivity of the researcher. This is crucial, given that, without the prior knowledge that I possessed at the start of this research project it is unlikely I would have been able to engage with this topic effectively. As noted, I did not want to come to the research with preconceived hypotheses about what the research might uncover, as it was more important to let the lived experiences of the participants unfold throughout the research process. Again, this is reflected in the methodology employed.

Within a critical grounded theory approach the existing research ideas and perspectives, alongside the literature review, can be useful to orientate and guide the direction of the study from the outset and in its subsequent steps. Whilst originally Glaser and Strauss (1967) suggested grounded theorists start with a blank canvas, they came to recognise the difficulties this may present. As I am deeply immersed in the topic both professionally and personally a blank canvas approach was impossible, nor would it have allowed me to develop the necessary engagement with the participants.

Charmaz (2014) contends that GT can closely align with social constructionism. This allows flexibility as it is not rigidly reliant on linear steps and processes. This combination also counters the potentially theoretical aspects of GT.

In this research this becomes a way in which to understand the construction of visually impaired people's experiences in HE by appreciating the way in which knowledge about the self, the societies in which we exist and the impact of these on experiences are created. Social constructionism is also applicable in relation to the experience of being a student in HE generally and of HE as a concept. If we accept that there are realities but that we are able to shape them socially, then arguably within HE, we are continually creating and re-creating what we know, what we experience and how we understand this. However, there are also limits to the freedom to create and re-create given overarching constructions within HE regarding students, curricula and environments.

Once concepts are related through statements of relationships into an explanatory theoretical framework, the research findings move beyond conceptual ordering to a theory, which is more than a set of findings; it offers an explanation about phenomena. The phenomena that evolve from and are explained by a theory are varied – work management, leadership, awareness, illness trajectories, safety, stigma and so on. Generating theories about phenomena, rather than just generating a set of findings, is important to the development of a field of knowledge. Theorizing is the act of constructing an explanatory scheme from data that systematically integrates various concepts through statements of relationship. A theory does more than provide understanding or paint a vivid picture. It enables users to explain and predict events, thereby providing guides to action.

Grounded Theory was envisaged by Charmaz (2008) as a set of systematic yet flexible guidelines for collecting and analysing qualitative data. This may be used as a fully self-contained approach, but it has been adapted and critiqued by various authors resulting in a flexible structure. Indeed, originators Strauss and Corbin

(1998) argued for a more mixed methods approach if appropriate. The aim, as Charmaz (2008) envisaged it, was to construct theories from the data – constructing a theory grounded in data. This begins with inductive data and employs iterative strategies of going back and forth between data and analysis, uses comparative methods and keeps the researcher interacting and involved with their data and emerging analysis.

GT serves as a way to learn about the worlds we study and a method for developing strategies to understand them. Charmaz (2014) states that we construct our grounded theories through our past and present involvement and interactions with people, perspectives and research practices – resulting in an interpretative portrayal, rather than an exact picture, depiction, or reflection. The initial stance of grounded theorists is exploration over confirmation.

### **Ethical Considerations**

I next turn to ethical considerations in the research process. I examine the ethical considerations of the study itself and the wider ethical history of researching with disabled people. The latter is particularly significant within the discipline of Disability Studies, so providing context for how this research was shaped, and influencing the choices that I made at every point.

I needed to ensure that there was accountability to the research participants, and transparency in the research aims. An ethical approach to the dissemination of information was important. For example, it was anticipated that all materials would need to be created in a variety of formats so that that participants could access the information relating to the study in a way suited to their own requirements. Given the varied nature of the requirements, information was made available via email attachment or a word document that could be inserted into the body of an email. I



anticipated this would be the case from the outset having worked with many visually impaired people. Whilst participants in the study may have requested information to be made available in Braille all were happy to have information via email, with a follow up phone call offered to discuss any questions they had, or to go over the information contained within the email.

For the group I was working with it was vital to be able to offer this to ensure all participants were fully appraised and aware of the purpose, the methods and the outcomes of their involvement. I endeavoured to ensure that there was much room for manoeuvre throughout the research process for participants and scope for them to offer additional input or feedback. Additionally, at every point within contact with participants, they were assured of their right to withdraw from the project at any time, and the ways in which their data would be stored. Equally I assured all participants of their right to anonymity and made clear my position as a researcher undertaking this project in partial fulfilment of a programme of study. In every contact with each participant I checked again that they were happy to continue and that they felt that they were fully aware of the expectations they could hold about my role as researcher and what they, as participants, could expect from the process. All participants indicated that at all points within the study they felt fully aware of the purpose of the research and their role within it.

I was particularly aware that, as individuals perceived as vulnerable by wider society, rigour was needed. I am particularly sensitized of the need to be accountable given the concern shown over time that research carried out with disabled people may simply further the interests of the researcher (Oliver, 1990).

Ethical considerations in this thesis, then, relate back to a history of what could be labelled unethical research about disability and on disabled people. Research carried out upon disabled people in the past has influenced the ways in

which research rooted in the promotion of the rights of disabled people has evolved, including my own.

The historical experiences of disabled people within research situations have been central to the development of ethically appropriate approaches in contemporary research with disabled people. Historically, disabled people have been subjects 'of' research, for example that which examined the causes and contentiously, the 'cures' of impairment. Now prevailing approaches to research with disabled people rightly challenge research 'done to' disabled people and instead champion enquiry which places disabled researchers and disabled people at the forefront of research into their lives and lived experiences, an unquestionably positive development.

Sensitivity to the history of research in this field is important here given that earlier work emphasised the eradication of disease and disability as an underpinning philosophy. Early eugenics programmes, such as the movements of the early 20<sup>th</sup> century in both Britain and the USA, as Snyder and Mitchell (2006) discuss, sought ways to counter disability and impairment but did not consider the value and rights of the disabled person within their outlook, often categorizing disabled people as in deficit or worthless. Research which examines the potential for eradication of impairment still exist within a contemporary landscape, for example in the ongoing medicalised trials and interventions which aim to reduce the prevalence of certain eye sight conditions and genetic traits. The Vision UK strategy (2017), for instance, reports on a gene therapy programme introduced to tackle retinal disease, supported by clinical trials and it has been proposed to the NHS that it make this available for the treatment of individuals with such sight conditions. Whilst clearly innovations such as this can be welcomed, there remains a tension in doing so.

Disability, from this viewpoint, continues to be defined as in need of cure and rehabilitation.

Other efforts to overcome what some have seen as the problematic existence of disability can be identified in even comparatively modern history, often enacted in brutal ways, for example in Nazi Germany. These efforts destroyed many disabled lives and were, simply, unspeakably horrifying. However, the idea of disability as a problem has nonetheless influenced the ways in which research has subsequently been carried out in Britain and elsewhere, delineating further those who were positioned as different. Additionally, ongoing campaigns and debates about the right to live or right to die serve to emphasise, again, the ways in which difference and disability are, or are not, valued and lives counted as important or unimportant. These debates feature in contemporary mainstream media, such as Hale's (2018) article in *The Guardian* which offers a powerful narrative about ongoing concerns amongst disabled people regarding campaigns in favour of assisted dying. These add to the melee of ways in which disabled people are examined within society, ranging from media representations, to research undertaken with, upon, and by disabled people.

How disabled people were positioned within historical research was contentious and problematic. Hunt (1966), for example, indicated that research was carried out on what were assumed to be passive subjects without regard for autonomous involvement. The assumption of passivity was partly responsible for calls by disabled people against being positioned on the fringes of society as a marginalised group without a say in their own lives and so it stimulated disabled people's activism. However, researchers that examined disabled people did not, for the most part, take such calls on board and continued making judgements about the lives of disabled people. In effect, pre-existing ableist perspectives meant that there

was little attempt to understand disabled people's points of view about what their own lives were like.

In response to this, the activist movements of disabled groups in the 1980s, such as that of the Disabled People's International (DPI) offered stronger challenges to the intrusive and overwhelming amount of research that was carried out. This became formalized in the slogan "nothing about us without us", adopted by many in the early 1990s, which was, in effect, a demand for self-determination, as summarized by Charlton (1998) amongst many others. It is therefore imperative to this research that it incorporates the ethos of 'nothing about us without us'. This also means that, ethically, this is research that aims to be emancipatory.

My choice of methodologies, as outlined earlier, ensured that I developed a methodological framework which took at its core a commitment to the rights of the participant group I was working with and one which ensured that disabled rights on the whole were strongly championed. This locates it in the area of emancipatory research, although only to an extent, as I indicate below. Emancipatory research serves as a benchmark which politicises and demands the promotion of rights within the research process. It is often discussed within disability research and, given the nature of emancipation, which as Freire (1993, p.44) states "is the great humanistic and historical task of the oppressed: to liberate themselves and their oppressors as well", positions such research as seeking to politicise the oppression of disabled people, liberating both oppressed and oppressor.

As suggested in the Literature Review, to be visually impaired appears to remain a significantly subjugated experience within contemporary society, an argument this thesis revisits in the discussion in Chapters Four, Five and Six. Despite the historical challenges to disability research production and the ongoing promotion of research which remains value free, or which seeks to empower, wider

society still often appears to dictate how visually impaired people are included. Emancipatory research, in terms of this thesis, seeks to commit to the politicisation of visually impaired people's participation within a fair and just society which challenges misconceptions and inherently ableist and thus oppressive practices and beliefs.

However, it is difficult to claim that any research is truly emancipatory, and this is indicated by there being ongoing discussions regarding what constitutes 'good' research with disabled people. In a sense, this is because emancipation is difficult to define Mercer (2004, pp.123-124) contends

'emancipation' as a research outcome can be measured in very different ways, as the self-empowerment of disabled people might take several forms: documenting social barriers and oppression, re-evaluating perceptions of disability, and taking political action. Furthermore, empowerment rarely entails a sudden conversion on the road to Damascus, or even a simple progression to social inclusion or 'liberation'.

All the same, this complexity does not mean that one should shy away from a commitment to emancipatory research, for as Mercer (2004, p.129) concludes, "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". This position offers a balanced approach to emancipatory research and tackles questions about how it is possible to 'know' that the research that has been carried out has reached the ultimate goal of emancipation.

Further, this research cannot be considered fully emancipatory given that emancipatory research demands disabled people to be in full control of the research process (Barnes, 2003; Goodley, 2016). Within this project participatory aims of

research were more appropriate along with a focus on interaction, for as Charmaz (2008, p.402) suggests, within a Grounded Theory approach “[t]he research process emerges from interaction”. Throughout this research the interactions that have taken place between participants and I have guided the research process and shaped the course of the interview process. For example, participants were keen to talk more widely about their experiences of being visually impaired, rather than solely on their experiences within higher education. It became apparent that the wider experiences helped them to explain how they experienced not only higher education but their daily lives as students when outside the university. These wider discussions shifted the scope of the research and so did justice to the importance of participants’ stories and experiences. I discuss this more in terms of the research methods later in this chapter.

So, whilst this research embeds a commitment to emancipation, it is more accurately described as participatory, given that the participants were not wholly in control of the research process. This approach has been significantly taken up within disability research as it can be inclusive on a range of different levels. What is most relevant to this research, combined with the critical reflexivity encouraged by both CDS and a critical approach to Grounded Theory, are the ways in which these approaches call for a strong researcher reflexivity and for research to be constructed between participants and researcher.

### **Summarising methodology and ethical concerns**

Research with disabled people has been heavily contested, and rightly remains so if the purpose of the research is not heavily invested in the politicisation and autonomy of disabled people. As a novice researcher it has been a challenge to develop a strong response to this in terms of methodological rigour and to ensure that the research can be shaped by the involvement of the research participants.

However, I have taken various steps to address this throughout the research process.

Grounded Theory is the guiding methodology of this thesis as it allows for the opportunity to deeply engage with the experiences of the participants and engages with my own researcher positionality. It is also able to inform the ways in which the data collection element of the project is undertaken and subsequently informs the ways in which data is analysed.

### **The research participants**

These brief pen-portraits give an overview regarding each individual. Their experiences are explored in more depth later in the thesis. The participants are as follows:

#### **Emily**

Emily is a woman in her early twenties, who has recently graduated from a university in the North West of England, where she read English for her 3-year undergraduate degree programme, graduating with 1<sup>st</sup> Class Honours.

Emily chose this university due to location, course choice and the initial feelings generated by her interactions with the university disability support services. Emily had previously studied at a specialist college for visually impaired people, based in the Midlands, taking part in the post-16 provision offered to visually impaired/blind students before moving to university at 18.

Emily has identified as visually impaired, with limited sight, due to a relatively uncommon eye condition. Emily is a guide dog user. She used Braille and assistive technology to access her course content.

## **Georgia**

Georgia is a woman in her early twenties who moved from Lancashire to the North East of England to attend university. She is currently writing her final year dissertation as part of a master's degree in Human Resources and Management, after successfully graduating from a Business and Human Resource Management undergraduate, sandwich degree programme.

Georgia moved here with her then partner, after attending an open day at her current university and being impressed with the quality of support that was offered. Georgia then remained in the North East after graduating, securing employment with a national caring organisation. Georgia works full time and studies part time which, she admits, can be a struggle.

Georgia attended mainstream education within a school which had a separate 'unit' specifically for visually impaired or blind students, until sixth form when she describes the withdrawal of support as quite forceful, stating that it consisted of "being made to be on your own".

Georgia has a congenital eye condition that is prevalent within her family. Georgia uses an iPad to access her course materials and books.

## **Maddie**

Maddie is a woman in her mid-twenties, who recently graduated with 1<sup>st</sup> class honours from a university in the South Midlands. Maddie studied Creative Writing at undergraduate level and is currently half way through a master's degree programme.

Maddie attended mainstream education until she went to specialist education for blind/visually impaired people in 6<sup>th</sup> form. Maddie describes the years in statutory



education as particularly difficult despite having what she feels was a very happy and idyllic childhood.

Maddie's time within specialist education was a revelation, leaving her feeling valued and an integral part of the Blind/VI community. Higher education, however, was not similarly experienced as membership of a supportive community. Maddie considered dropping out at a number of points.

Maddie is a guide dog user. She has no light or dark perception and cannot see shapes or colours. Maddie reads Braille and uses assistive technology.

### **Naomi**

Naomi is woman in her mid-twenties who identifies as having relatively 'good sight' in one eye. She attended specialist education from the start of secondary education.

Naomi attended university in the North West of England, studying media and communication at undergraduate level. Naomi chose this higher education institute due to the course, the support she believed she would be offered and its proximity to home.

Naomi now works in the voluntary sector with visually impaired adults.

### **Leah**

Leah is a young woman in her 1<sup>st</sup> year of a foundation degree programme in the North West of England. Leah attended specialist education prior to university.

Leah is enjoying university and lives in halls of residence on campus.

### **William**

William is man in his late twenties, who attended a university near to his home in Southern England. William has a relatively rare eye condition that developed as

he was completing his A-Levels in mainstream education. William went to university to read History as a newly visually impaired person.

William graduated recently and now works in the voluntary sector with visually impaired adults and is an active participant in sporting activities for visually impaired people.

### **Luke**

Luke is a man in his late forties who has attended university for a number of programmes, including one for a degree which confers a professional status. Luke is currently undertaking a further professional qualification.

Luke is an active participant in the visually impaired and blind community in the North East of England and has been since his sight changed in his later teenage years. Luke identifies as having a hidden disability in relation to his sight.

Luke attended mainstream education.

### **Martin**

Martin is a man in his mid-fifties who lives in the North East of England and travels periodically to the Midlands to attend university where he is studying a professional qualification as a distance learner.

Martin identifies as having relatively good sight and is an active member of the visually impaired community in the North East.

### **Peter**

Peter is a man in his late twenties, who read History at a redbrick university in the North East of England. Peter has no light or dark perception and is a guide dog user. He attended mainstream statutory education, with specialist support.

Peter works in the voluntary sector with visually impaired children.

## **Sampling, recruitment and building rapport**

Moving on to the practical aspects of designing the project, the following sections discuss the ways in which participants were identified and recruited, sampling, the methods of data collection and analysis of the data. I begin by explaining how I approached identifying and engaging participants.

As the research aimed to investigate VI students' experiences in HE, participants were anticipated to be drawn from visually impaired people who were either currently participating in higher education or who had recently been in higher education. The project could have incorporated those who had studied during any period but given the rapidly changing nature of HE and that its current form has a specific ideological inflection and set of constructions, it was decided to focus only on recent experience to ensure these were comparable accounts.

All the same, given the small number of visually impaired students in HE, as noted in earlier, to limit to only those who were currently studying may have added an unnecessary constraint to numbers. I originally sought to involve between 10 and 12 participants and adding a further limit may well have caused additional issues with recruitment.

Initially the recruitment of participants was broadly purposive, using the simple criteria for recruitment discussed above. Purposive sampling, as Denscombe (2010, p.35) argues, seeks to find, "the best information through focusing on a relatively small number of instances selected on the basis of their known attributes" and can be a way of ensuring those who have specific experience of a topic are sought out.

Upon ethical approval, which was granted in the first year of the project, 27 universities were contacted by email and asked if they might be willing to

disseminate information regarding the research to visually impaired or disabled students studying at their institution. These universities were located within the North East, the North West and the Midlands. This was an attempt to create a broad range of data collection opportunities that were manageable within the time frame and within the limits of the resources available for travel.

Within this email, I identified myself as a researcher at Northumbria University who was seeking visually impaired students who would be willing to take part in a short series of interviews to talk about their experiences in HE. I provided a summary of the research project; the methods of data collection and what participants would do if they took part in the study (see Appendix 1). I offered, within this information, a full assurance of ethical approval in relation to the research and of confidentiality for all participants. I provided two methods for participants to contact me, either by telephone or email as these were methods likely to suit the needs of the participants.

Initial responses were limited. Only two universities were willing to disseminate the research information, as many stated that they wished not to bombard their students with requests for research participation. This suggests a degree of protectiveness of students, given that potentially a number of requests may have been received, but might also reflect a concern about university practices being scrutinised, suggesting an element, potentially, of image management. Others signposted me to organisations such as the Students Union and suggested that posters and flyers be disseminated across their buildings to advertise the research. Given the topic area and the potential limits associated with the inaccessibility of posters and flyers for the intended participants, this seemed to add an unnecessary extra limitation, or reflect a degree of thoughtlessness regarding the implications of being VI or blind.

A secondary attempt was made to seek participants via universities based in Scotland, which again yielded limited results. Similarly, specific Further Education (FE) colleges offering educational provision for VI students were contacted. Despite following up on this initial contact, few participants were forthcoming. This indicates how challenging this phase of research can be. In writing about this issue Kristensen and Ravn (2015, p.731) suggest that,

the recruitment process is emotional work that should not be underestimated. Researchers must be persistent, must follow-up on calls that are not returned, must send reminders and must repeatedly 'sell' their projects to persons they do not know. No matter how professional researchers are, they may suffer personal costs from being repeatedly turned down, and embarrassment and faintheartedness can easily become their daily partners in a slow recruitment process.

Whilst indicative of the time taken to approach gatekeepers in the form of universities and as such which should not be underestimated, being flexible and seeking alternative ways to locate participants yielded results.

The change to my approach was prompted by the way that the small number of VI students who expressed interest in participating in the research as a direct result of the original mail shots suggested colleagues, friends and peers who might be interested in participating and asked if they could pass on my contact details. This yielded an increased number of participants who expressed an interest in taking part and diversified the geographical areas from which participants were drawn. This meant that the final group of participants was, in effect, a snowball sample, something which Denscombe (2010, p.37) states occurs when, "participants refer the researcher on to other potential participants" and can, he argues, be greatly beneficial for seeking out additional or new participants. Whilst this may be a planned strategy regarding research participants, this was not the case here, but rather a fortuitous accident. That people willingly suggested further contacts implies that they have personal networks, whether simply motivated by

friendship, or for mutual support, that universities and other institutions are unaware of. Whilst largely beyond the focus of this thesis, this is suggestive of structural issues within institutions regarding their support or understanding of specific groups of students.

In addition, Denscombe (2010) asserts that snowball sampling helps to offer potential participants positive credentials regarding the researcher and identify participants who share similar characteristics to those who are participating already. However, snowball sampling means that any sample is not an entirely representative one. All the same, Cohen, Manion and Morrison (2011, p.161) argue that, given, how much importance is placed, within qualitative research, on the “uniqueness, the idiographic and exclusive distinctiveness of the phenomenon, group or individuals in question... how far they are representative of a wider population or group is irrelevant, as much qualitative research seeks to explore the particular group under study, not to generalize”. Finally, cost efficiency, speediness and suitability for a smaller scale research project (Denscombe, 2010, p.37) are associated with this method, making it suitable here.

Of the thirteen people who were interested in taking part, two participants withdrew from the study due to work commitments, leaving eleven participants who came from a diverse range of backgrounds and localities, and who had all identified as having varied experiences of HE. Two further participants could not contribute to the project due to changes of circumstance, leaving nine. Of these students, four identified as male, all ranging from age from mid-20s to mid-40s; The remainder of participants identified as female and were much closer in age range - from age 19 to mid-20s. Within the group there was a diverse range of backgrounds and current life circumstances, with two students (male, later age range) identifying as from working class backgrounds, which they intimated had developed towards middle

class as they progressed in their careers. All participants identified themselves as white and from the UK. In summary, all of the students within the research live in the UK and have recently completed or are currently studying at British universities. In initial discussions with these participants, given issues around location and ease of travel, a small number asked for the interviews to be carried out via Skype or telephone.

Initially, in discussions with participants, Skype as a medium felt adequate to address some of the complications associated with geographical spread of participants and associated limitations of time. However, its use was withdrawn as a method to support the interview process because, as noted within the Skype terms of use, there is a suggestion that information sent over the network can be reviewed in relation to the associated terms and conditions of Skype itself (Skype, 2014). Furthermore, Garfinkel (2005) notes that where conversations appear to be encrypted these are actually discoverable via the network and whilst in terms of the content of the conversations anticipated it was felt there was little of value to others that these conversations were likely to include personal information and personal experiences that an alternative method should be used. Most participants were happy to conduct interviews in person where geographical and time limitations allowed, and for those that were unable to meet face to face telephone interviews were sufficient.

All these circumstances chime with what Creswell (2012, p.44) contends when stating that “the research process for qualitative researchers is emergent... [so] the initial plan for research cannot be tightly prescribed and, and that all phases of the process may change or shift after the researchers enter the field and begin to collect data”. In effect, the design of this research altered to suit a more fluid approach given the direction and input from the participants.

All the participants felt the project was personally relevant, but also that their experience had the potential, through the research, to impact upon HE. Their enthusiasm about sharing their experiences and working with me in directing the shape of the project necessitated flexibility within the research process, as noted. This was imperative to my underlying commitment to its co-construction. In addition, it was also beneficial in building rapport, which Charmaz (2014, p.33) notes is a way to respect research participants. As Watts (2006) discusses in relation to her examination of an insider/outsider research relationship, building rapport is crucial. She insists that trust building between participant and researcher is vital alongside academic rigour and confidence that what participants share is used positively. To some participants I was an unknown quantity professing insider knowledge about visual impairment and so building trusting relationships was crucial.

Before the interview process, rather than expect participants to solely engage with the information pack that was sent to them via email, I engaged in a brief email or telephone conversation, for those that requested it, to clarify what their involvement was to be and what the purpose of the research was. I hoped that this would help to build relationships with the participants and begin to co-construct the research experience. As several participants were introduced to me via other participants, I felt it crucial to engage with them at certain points prior to interviews. As Charmaz (2006, p.61) notes, grounded theorists often have to negotiate complex settings which require fluency in the language or procedures within, and it was of importance to reassure participants that my position, knowledge and understanding, was as it had been told to them by peers.

However, equally important is the relationship I had with participants to whom I was already known. The relationship between myself and a small number of the participants pre-existed this research, one through a professional relationship, and



for another two as acquaintances in broader social circles. Whilst arguably this helped to open the discussions through ~~our~~ shared knowledge about topics and each other, there remained a strong need to ensure that this pre-existing relationship did not have a negative effect on those participants. This was managed similarly, ensuring that participants were aware of the intention of the research and a continuous commitment to anonymity and informed consent.

### **An ethical interview process**

Interviews are particularly useful when collecting data that is based on, as Denscombe (2010, p.174) articulates it, “opinions, feelings, emotions and experiences... sensitive issues... privileged information”. Semi-structured interviews are widely used within qualitative research methods, one of the most common methods for information gathering (Flick, 2006). Given the propensity of qualitative researchers to revise their interview questions based upon experiences in the field (Creswell, 2013) and given that the aim of the research was to investigate experiences more deeply, the semi-structured interview allowed for significantly diverse and in-depth recounting of experience and multiple perspectives. As Denscombe (2010) contends, semi-structured interviews give participants a greater autonomy to develop and expand on points they feel are of interest. This type of interview can demonstrate rich data regarding a range of topics and allow the participant to discuss wider angles to questions beyond those envisaged by the researcher (Bryman, 2008). Hesse-Biber and Leavy (2011) note that the use of semi-structured interview allows participants the freedom to talk about what is of importance or interest to them, rather than be guided by the interviewers understanding of what the salient points may be.

Initially I had anticipated that a more varied approach to data collection would be engaged. Other methods of data collection which were considered were walking

ethnographies, spending time with participants. However, given that many participants already felt that they were often conspicuous as visually impaired students within their environments this method was dismissed. Additionally, many participants take part in other activities, away from the universities but as part of their day to day lives, including sporting and leisure activities both with other visually impaired and non-visually impaired friends and peers. Again, this method felt tricky to negotiate, given participants' anonymity and again, their feelings about their conspicuousness. I engage here with an extract of my research journal which identifies my thoughts around this: *"...if I am on campus and attending social activities with students, or even just being around, will this not impede on their participation? How can this be overcome? Perhaps, it would be better if I was more withdrawn and did not infringe on day to day activities..."*. Personal Research Journal (2017).

In the end, logistical constraints rendered using other methods impossible due to participants' commitments to revising and undertaking exams, or other activities which limited their free time. Participants consequently determined the methods, so guiding the research, by suggesting that they would prefer the opportunity to talk in one-to-one interviews rather than carry out other kinds of activity. This was a pragmatic decision that enabled all of us to use time efficiently.

Before commencing the data collection across all participants, a pilot interview was carried out. This engaged with initial questions such as "Can you tell me about your reasons for choosing higher education", "can you tell me about your experience contacting the university"; "Can you tell me about your experiences with the Student Services within university". Whilst these questions did yield responses which highlighted experiences, these felt too limited and led to a revision of the questions and a stance of a flexible loosely semi structured

interview process. Pilot interviews, Bryman (2008) suggests allows for the researcher to examine the types of questions which will be asked and assess the usefulness of such questions. Additionally, within my research journal my reflections on the process of the pilot interview helps to move the process forwards. I realised that there were opportunities being missed to explore fully visually impaired student' wider university lives as they recounted them. I include below an example of my research journal as I explore what this might mean for the direction the research might take. *"I spoke with XXXX today, really interesting, they were talking about their experiences travelling as they had just returned from a trip. What if this could be drawn out? I think it would add a huge amount to the ways in which these experiences help us to understand what it is that day to day life is and how this and the experiences within HE impacts on each other and are influenced by each other."*

After this I contacted participants and asked if they would be happy to explore some of their daily experiences within our interviews, a process that had not been explicitly mentioned before, yet which as part of the interview process had begun to happen. I reflected that *"important parts of the research would be excluded if we stuck to a rigid semi structured interview process. I would feel uncomfortable taking out the person within the research process"*. This examination and reflection led to altering the way in which I gathered data through the interview process.

After carrying out the pilot interview (Bryman, 2008) the initial premise of a single semi-structured interview was revised, both to better explore participant's recollections, and to ensure that interviews were in line with the desire to carry out research guided by an "emphasis on understanding the research participant's perspective, meanings and experience" (Charmaz, 2014, p.56), were open-ended

and encouraged exploration. As Charmaz notes in relation to interviewing participants, grounded theorists want to interview participants who have experiences which can elucidate the topic they wish to study. I chose, rather than rigidly abide by a strict interview schedule, and to allow for participants to guide the direction of the interviews, to work with prompts that were loosely structured around certain topics – such as accommodation, DSA, or access to course materials. Participants were simply asked to describe experiences that they felt were indicative of their own lives. This meant that “the participant talks; the interviewer encourages, listens and learns” (Charmaz, 2014, p.57). At this point, to illuminate further the importance of getting the right interview process which encouraged a freer discussion I share here an extract from my research notes.

I had estimated that interviews would take around an hour for each session as I felt this maintained a schedule without constraining participants’ freedom to recount their experiences. In the end interview length varied, but this was indeed the approximate time of each. Despite my concerns that an approach which relied solely on interviews carried out in a sequence over a period of time, often with gaps enforced by other commitments, might not allow for a deeper understanding of their experiences, the interviews yielded far more in-depth information and retellings than I had initially anticipated, in part because of the use of an approach which allowed for an extended and reflective dialogue across several encounters. Participants were pleased to talk about their experiences, particularly, as some expressed, as they had never been asked about their experiences at university or even about their lives in general. This is potentially telling regarding university practices, which ideally might consider student experience in improving services.

These were not single interviews, which may be seen as retrieving information from individuals in a potentially exploitative manner rather than engaging

in a more iterative, inclusive and co-creational process (Charmaz, 2008). Further, May (2001, p.136) contends that no single interview can offer more than “limited insights into general social forces and processes”. Returning to individuals with my reflections on their previous interviews, in effect discussing my thoughts with those involved in the research, allowed both to further reflect upon the process and directed additional discussion. These opportunities for reflection and discussion were part of what the participants intimated they had gained most from in taking part in the study, with many suggesting that the process they had undertaken of reflection upon their experiences was of benefit to them, particularly in the time between the first and subsequent interviews and discussions.

Prior to the first interview with each participant I discussed key ethical issues with them, including informed consent, confidentiality, accountability, anonymity and their right to withdraw. Confirming all participants were happy to proceed I sought verbal and written consent and confirmed that each participant was content to have interviews recorded. Further, as discussed above, the idea of offering participants a reflective space and returning to discussion, thus supporting individuals within the process can be seen as part of the wider ethical dimension of the research.

### **Analysis of the data.**

Denscombe, (2010, p.114) contends that analysis of data involves “the separation of things into their component parts... involves the study of complex things in order to identify their basic elements. It calls on the researcher to discover the key components or general principles”. If, as Braun and Clarke state, researchers “do not wish to produce a fully worked-up grounded-theory analysis” (2006, p.8) an alternative means with which to analyse the data is to engage with a thematic analysis which draws out key themes in the data (Bryman, 2008, p.700) and then divides them into core themes and subthemes (Bryman, 2008, p.554).

Thematic analysis is a flexible tool not limited or constrained by allegiance to specific theoretical positions (Braun and Clark, 2006). This method has commonalities with Grounded Theory, as well as several other approaches (Attride–Stirling, 2001).

Where a Grounded Theory approach has the ultimate aim of generating theory (Charmaz, 2008) thematic analysis does not inevitably lead to this conclusion. In this research, the aim was not to develop an overarching theory or model, but to provide a way for a typically under represented group to share their experiences, so reflecting its' co-constructive nature. However, it does aim to explain and offer predictions about what might happen, or continue to happen, and so stimulate action, regarding the findings, as GT is intended to.

Thematic analysis as Braun and Clarke (2006, p.9) contend, can be “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”, highlighting a commonality with the aims of this research. Thematic analysis is therefore a useful tool with which to examine the participants' experiences.

### **Working with the data**

Each recorded interview was transcribed as part of the data collection and analysis process. This was a time-consuming activity but helped to clarify my thoughts about each interview and reminded me of salient points and initial ideas stemming from them. Thus, I followed that which Braun and Clark (2006, p.87) note are the distinct phases of thematic analysis, “Familiarising yourself with the data; Generating initial codes; Searching for themes; Reviewing themes; Defining and naming themes”, adding that “familiarising yourself with the data allows you to develop a thorough understanding”.

Familiarisation with the data, which developed through both transcription and reading the transcripts, as suggested above, generated ideas about content and initial coding of themes. Examining the data in this way allowed for the development of a basic organisational structure for it. This was an iterative process; each code was revisited and formed the basis of the following phase whereby the data was re-examined to search for themes. This phase developed once the data has been sufficiently coded by analysing the codes and sorting them into potential themes.

Initial examination of the data highlighted several themes that appeared strongly in every transcript. These themes were overarching, and it later became apparent that each contained smaller subthemes. After completion of the transcription of the participant interviews and the initial examination, each transcript was examined further to identify themes that bore relevance to my research questions. I numbered these themes and collated them in order to scrutinise them further. Clear patterns emerged, and additional re-reading of the transcripts highlighted the prevalence of these themes. At this point I converged the themes and created defined sections within a Word document with space to allow for edits and alterations.

This process yielded around 20 initial themes and by re-examining them I could move to a more focused analysis of the themes.

### **Generating and reviewing themes**

After familiarisation with the data, I examined the transcripts again using the initial themes I had identified to draw out overlaps that might be obscured by alternative wordings of an answer or where a participant related a slightly different experience that was similar in theme to that of other participants, an important part of the thematic analysis process as discussed by Braun and Clarke (2006). A larger

number of initial themes were examined, searching for overlaps, moving and re-coding themes in different sections as “no data set is without contradiction, and a satisfactory thematic map that you will eventually produce - an overall conceptualisation of the data patterns, and relationships between them - does not have to smooth out or ignore the tensions and inconsistencies within and across data items.” (Braun and Clarke, 2006, p.19).

After reviewing the data, checking and rechecking themes, this left me with a smaller number of themes that were strongly rooted in the data yet contained several subthemes. As Braun and Clarke contend, “Data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes” (2006, p20). The main themes that emerged were:

- Societal responses to, and constructions of, visual impairment
- Institutional responses to, and constructions of, VI students
- Visually impaired students’ identities
- Responses to visual impairment from peers and other students
- Power relations within university and other structures in relation to VI

A number of smaller subthemes were apparent within each of these key themes, including:

- Accessing the university/DSA/Accommodation
- Course Materials and resources
- Responses by support staff
- Responses by academic staff
- Being visually impaired in university



- Being visually impaired in day to day life

This review of the themes highlighted that some had merged, particularly in relation to accessing the support required to in turn access university via support services and DSA assessments. These themes were dealt with separately at first and then brought together. However, it became apparent that these themes were distinct and required more individual analysis to effectively draw out the strong stories about what these experiences had been like for the majority of participants. This chimes with Braun and Clarke's (2006, p.20) suggestion that "data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes," and that where themes do not coherently meld together there needs to be a consideration about whether these themes fit together, or if there needs to be a new theme, or if the data should be discarded from the process entirely. Rather than discard the data, as it was clear that these themes were significant, given how much rich data about their experiences with support services and assessments appeared, these themes were separated into individual sections.

With regard to confirming themes within the analysis Braun and Clarke (2006, p.25) remind us that "the extracts in thematic analysis are illustrative of the analytic points the researcher makes about the data, and should be used to illustrate/support an analysis that goes beyond their specific content, to make sense of the data, and tell the reader what it does or might mean". Analysis of the themes highlighted the complex nature of the participants' experiences and confirm that there are many areas of interest within their retellings. The final chapters explore the potential meanings of aspects of that experience.

## **Limitations of the study**

Whilst there is much rich data in the interviews about the wider experience of HE, a higher number of participants could potentially have further increased the amount. The small number of participants is likely to be linked to the small numbers of visually impaired students within higher education. However, one could also speculate that disabled people are currently subjected to much academic and policy research and may thus be less willing to participate within research such as this.

Accessing participants through formal networks proved problematic. This perhaps reflects that the ways in which the information was disseminated by the universities was inaccessible. Where universities did share details with potential participants there was some uptake from students. This could be related to my eagerness to avoid positioning myself as an expert researcher. This may have meant that universities did not want to disseminate the information to students, despite my ethical clearance. Whilst my novice status and informality worked well with participants, it may have seemed inappropriate to gatekeepers.

I am also conscious of having used informal networks in recruitment. Whilst this was successful, what informal networks do exist are rightly populated by visually impaired students and not professionals, and appearing in this space as a researcher felt uncomfortable, even though I was invited in. I sometimes felt that I was appropriating them for the purposes of this research and so felt disingenuous, especially given my underpinning desire to ensure the research was rooted in a commitment to visually impaired people and their autonomy.

Finally, whilst maintaining a commitment to the entire process of grounded theory may have generated theory, I was conflicted about making that the final aim of the thesis. In a sense, whilst GT guided much of this research, it was the

narratives and experiences that I wanted to make the focus. These have not been shared often previously and making a theoretical construction the point of the process felt like privileging the role of the researcher rather than representing their voices. There was, therefore, a tension for me in the research process around potentially invalidating the value of the research participants sharing of experiences and, in turn, of the experiences of disabled people more broadly. All the same, I do draw conclusions through analysing their accounts which could be a useful lens through which to analyse participation in HE.

## **Chapter Four: Constructions and contexts.**

### **Constructing the visually impaired student in the context of higher education**

The following chapters incorporate both discussion and findings as they have emerged from the research undertaken with the participants in this study based on the categories and subcategories that arose from the thematic analysis. In this chapter I discuss how the participants talk about their experiences of the practicalities of being in HE, so revealing a number of tensions between the two paradigms of HE and VI. The chapter divides into sections addressing specific areas of experience, these being accommodation, Disabled Students Allowance, assessment and the resulting adjustments, technology and assessment arrangements that are established as an outcome of the assessment. I use this chapter to critically engage with the ways in which the experience of the participants highlights that there are many issues associated with being a visually impaired student and the tension this brings about with standard university practices positioned as participatory. Here the paradigm of HE as inclusive comes acutely into tension with that of VI, and of the VI student.

I explore these tensions by employing a CDS approach. I note the difficulties associated with typically homogenous approaches to adjustments and assistive technology and argue that this indicates a deep-rooted ableist construction of the needs of the visually impaired student. I draw out that visually impaired students are the subject of many disabling interactions and approaches and identify and analyse the ways in which these participants take on board these constructions and where they offer up resistance and challenge. In doing so I address research questions two and four – How does the experience of being visually impaired in higher education impact upon the individual and how does the individual have an impact upon higher education, if at all?; and In what ways is the concept of participation

played out in relation to accounts of the experience of visually impaired students in higher education?

When I discuss access in this chapter, I specifically address the issue of access to the university environment and the various aspects featuring within this. As the findings show there is a lack of understanding within the HEIs the participants attended about what constitutes access that is suited to visually impaired students. Instead there is a consistent 'one size fits all' approach to access, which draws strongly on constructions of ability/dis/ability and so shows the ableist nature of individual university environments, whilst also serving to imply that there may be wider issues within the sector. In analysing access, I draw out the theoretical underpinnings about the space that disability, and thus visually impaired students, are likely expected to exist within. I also then examine the ways in which this underlying expectation delineates who should and can participate in higher education regardless of policy and legislation. I show, as in previous chapters, that for visually impaired students these expectations create tensions which position them as other and construct the participation of visually impaired students through a specifically ableist lens.

### **Returning to the pathologised student identity and the Disabled Students Assessment**

As noted previously, from the outset of their journey into university disabled students are positioned within a medicalised dichotomy surrounding access to support and, particularly likely with visually impaired students, access to assistive technology. For students who identify an impairment in order to access support, assistive technology, or differentiation to their learning and living environments, there is a requirement to undertake an assessment to evaluate their needs in relation to their impairment. All participants within this study were involved with this

process, known as the Disabled Students Assessment (DSA). DSA is currently undergoing a number of changes (BIS, 2015), but it is pertinent to reiterate the basic premise of it here. DSA is currently paid to the student or to the organisation providing a service or equipment, upon completion of an assessment, assuming a student meets the eligibility requirements to be classed as a disabled student. The assessment cost is paid for from the award of DSA and is a requirement of the assessment process. After assessment, the student is provided with a report of the equipment and/or support allocated.

Including DSA under the banner of participation allows us to examine the processes positioned as tackling aspects of access deemed as exclusionary, such as access to assistive technology and support as tools to challenge inequalities in the learning environment. However, the existence of the DSA in HE correlates with Michalko's (2002, p.133) identification of the ways in which 'special education' insist on acceptance and adjustment, which he identifies as ideological practices. It also highlights, that from the outset the dominating positioning of medicalised discourses continuously create and re-create a dis/abling landscape (Goodley, 2014). As Mallett and Runswick-Cole (2012, p.37) note, "impairment labels often act as a shorthand for the identification and explication of a specific impairment 'thing'". In this instance I apply this to the process of becoming constructed as a visually impaired student. This emphasises how taking on board the role of being impaired brings with it several already predefined and assumed characteristics and a range of particular needs and requirements. This homogenised view is characterised in the following excerpts from interviews with those participants who due their initial assessments have been positioned within a view of visual impairment representative of wider societal mis/understandings and constructions of visual impairment and blindness.

For example, Georgia shared her experience of an undergraduate DSA assessment as follows:

*The whole DSA assessment was a joke but you know... You have to go through it and it is, like, a good two and a half hours long and I had to wait 'til February to get it, anyway! So, it was really late, anyway and I just felt like it wasn't particularly helpful to what I needed, it was more like and this is what a blind person gets, so this is what we are going to give you. In the end, I didn't really use it...*

Georgia undertook a DSA assessment prior to her course starting yet did not receive the equipment designated for her until the start of the second semester, a waiting time of around four months. She was able to purchase her own laptop and claim the funds back from her DSA allowance; however, this left her waiting for funds to be returned to her, eventually receiving only a percentage of her total outlay back. This corresponds with the findings of Jacklin et al (2009) who noted that an important factor in disabled student's participation and feelings towards their experiences in higher education is the absence or delay of support or equipment. They suggested that when students had these in place this had a positive impact on their feelings towards HE. Additionally, the longitudinal multi-agency research carried out by Hewett et al (2017), similarly identified issues with receiving equipment.

As Georgia's experience shows the delay in receiving equipment to assist with accessing materials and course related information placed her in a position whereby she was disadvantaged in comparison to her peers. Not only was this likely to have promoted a feeling of exclusion, this also highlights a disparity between the ways in which students who are disabled and those who are constructed as non-disabled are able to access higher education. Whilst Georgia is physically present on campus, without the right equipment to access course and university information she is unable to access the same information as others and thus this convoluted and drawn out administrative process tells disabled students that they are only on the fringes of participation. Whilst the university she attended argued it was

inclusive, the practice in relation to DSA suggested that this was not a fully understood concept.

Georgia's account includes an assertion that to access the funds that make up her DSA one has to accept that '*you have to go*' to the assessment. This compulsion exists regardless of any pre-existing educational recommendations that may have been made based on practical use, or on personal preference. In identifying as a disabled student in higher education, Georgia highlights that that requires an acceptance of the role that disabled students are expected to play in terms of 'coming out as disabled' and thus taking on board the connotations associated with that role. Georgia's identity as a disabled person is laden with an expectation "to embrace, indeed, to assume an identity other than one's own" (Campbell, 2009, p.11) whilst additionally accepting the expert knowledge which pathologises disability. Students who do not identify as disabled are not required to undergo any similar assessment, even regarding those who have caring responsibilities or who are from other marginalised groups and may benefit from involvement with personal tutors or support services prior to the commencement of their academic careers. This again shows how disabled students are positioned in terms of deficit within the structures of HE.

Finally, when Georgia summarises her experience by saying '*and this is what a blind person gets, so this is what we are going to give you*' she explicitly signposts a homogenised and stereotypical figure. She also locates this construction as at the heart of the DSA in her experience. This means she began her university study aware that she was considered to have predefined characteristics and a range of particular needs and requirements. She was also aware, as her comments suggest, that what she was offered bore little resemblance to her actual needs, a failure of the university services to recognise her as an individual.



## **Equipment and accessible technology**

Nearly all the participants who discussed the accessible technology and equipment that was provided after the DSA assessment expressed a clear concern about the ways that these assessments were translated into the purchasing of equipment and technology. They also commented on their lack of input regarding what was purchased. Much of the equipment made available was either equipment unnecessary or items they were unfamiliar with. Even for the participants that felt they had a little input into the choice of items there remained a frustration that their views were not listened to or considered. Again, they are constructed as in deficit, as antithetical to the ideal student, and so VI is once more positioned as in tension with HE.

Georgia's account relates her experience of the lack of input that she was afforded in terms of choice about equipment. After the DSA process she was provided with equipment that she was found problematic or was irrelevant. This was despite her voicing her views about the suggestions made to her.

*I got a printer and software, a scanner and a voice recorder for lectures and loads of stuff like that. I used the printer, but I didn't use the specific software as it was too awkward and took me too long to get used to. It was where you scan your textbooks and then it reads them out to you.*

*They said what sort of things have you had previously (in the DSA assessment) and I said well this, but it wasn't really that good and I have had that and that didn't really work... So, I didn't really use any technology they could provide but they gave me all this stuff I didn't really feel was necessary.*

Where the financial resources associated with the DSA process are managed by the support services within the university if, as is shown within these accounts, this is not suited to the individual student's requirements it raises questions surrounding the motivation and thinking behind the way this is allocated. It suggests the existence of a hypothetical blind student, one who is assumed to be passive, grateful, and accepting of what they are given, homogenising diverse experiences.

This is almost a tokenistic response to a generalised notion of visual impairment, essentially ableist. This allocation of unsuitable equipment was not unique to Georgia's experience, but appeared in most accounts. For example, as William recalled:

*Sometimes I think they were trying to help too much, in a way. I came up with a list of equipment that might be quite useful and then they added to it and it was just overkill, like I got a mouse! I can't see a mouse on the screen, what use was that!*

*I had only just learned Braille and they gave me a Braille display that just gathered dust. All this equipment, brilliant but I just didn't need it... I think it might be a case of not leaving any stone unturned, like this guy has just lost his sight, does he really know what is out there for him?*

William's account indicates that the process of acquiring support and accessible equipment relies on a power imbalance between himself and the assessors, as does Georgia's. This reflects how the imparting of expert knowledge pervades and dominates participants' accounts of their experiences. William's retelling plays this out in a mainly positive way, considering the staff as trying to help, implying they are overcompensating given an unvoiced concern about him. However, it highlights an underlying tension regarding the level of power that William was able to assert and a belief within HE that qualified professionals are the only people suitable to define support requirements. There is a distinct ableist tone apparent in both he and Georgia's relationship with the assessors.

Georgia's account is negative, even angry, regarding the waste of resources and lack of consultation. In contrast William's tone is more surprised, perhaps because, as he says, he is "*this guy [who] has only just lost his sight*", so such processes are comparatively unfamiliar to him. Indeed, the question "*does he really know what is out there?*", appears to identify the DSA process as an altruistic means for the university to provide him with equipment and resources that he may be unaware of or not previously had access to. This could be seen as suggestive of the

ways in which a construction of participation is created by those in a position of power, in this case the support services within the university, and the assessor who delineated support requirements, so aligning with Bolt's (2005) assertion that an ableist society renders a person disabled.

William was given additional equipment of no benefit to him, as was the case for Georgia. The underlying assumptions by the assessor about William's needs, imply that the assessor thinks that William's impairment means that he cannot possibly know what he needs. William therefore cannot be the expert on the subject of his own life. Whilst the process is intended to overturn exclusion, it may serve to compound it. That support has been given seems to the point, not that it is useful, a dismissive way to deal with students. The Equality Challenge Unit (2018) states that students must be involved in decisions about their support and any reasonable adjustment and also that the knowledge of experts is significant in this process: "It is advisable that staff who are experts in providing support for disabled people, and staff who have knowledge of particular barriers... are also involved in this decision" (accessed 11/9/18). What comes through in the participants' accounts, however, is that they as students are peripheral, not central to the process. The advice of the Equality Challenge Unit (2018) attempts to offer a social model, yet the advisory information is heavily inferenced with medicalised discourses about impairment. William's account is indicative of the troubling nature of attempting to work within a landscape that is heavily rooted in medicalised and ableist notions of disability, whilst attempting to provide support based upon an overly simplistic and reductionist societal barriers approach.

Applying a social model perspective as a 'one size fits all' approach to tackling ingrained and inherent beliefs about disability means that there is an imbalance in the ways in which disability and impairment are actually understood in

practice. The duality William experiences indicates how the social model is often engaged with and implemented by non-disabled people as a way to tell disabled people how they can overcome the external limitations associated with disability. This is without engaging more deeply with the actualities and realities of impairment and disability. As Michalko (2002) contends, like the discipline of medicine, the social model does not conceive of the body as natural and not as a social entity. This is apparent within William's account, as the broad application of the social model, in attempting to provide solutions to the structural and theoretical barriers that William is experiencing, removes the naturalness of human condition and places it within a dimension that holds disability as a medical phenomenon and not as a social entity suggesting that, "neither approach conceives of the "natural body" or impairment, as themselves cultural representations" (Michalko, 2002, p.56). This application of the model could be seen as additionally serving a purpose of maintaining a false reality – that by implementing solutions positioned to satisfy policy and to inform the existing rhetoric about disabled people, the actual experience of being a disabled student remains constrained within an overarching oppressive and ableist position, which places value on what Goodley (2014, p.xiv) describes as "smooth forms of personhood", here associated with seeing and as such deviation from this signifies "ableist normativity" (Goodley, 2014, p.22) which reifies the dominance of certain societal groups over others.

William thus is required to accept the narratives about the needs of the disabled student and an associated understanding of that student as incompetent and passive. Additionally, his comments suggest both the existence of the Kleege's (2005) 'hypothetical blind man' and his questioning of that construction through his comments about his experience. Equipment and support can, of course, be tailored to individual needs and resources managed efficiently in terms of genuine benefit to

students, as dictated by the recipient. Inclusive practices would thus be at the heart of support for the student, if the power structure were altered to allow the student to have control over and work with those who carry out the assessments, as opposed to being told what it is they can expect, with the added implication that they should be grateful for it.

Emily also experienced a DSA assessment that resulted in her receiving aids that she was not familiar with and that she felt were not of benefit to her:

*I remember my DSA assessor thinking that a Braille 'sense' would be really useful for me to have and pushing for me to have one and me saying well I have seen them before, and I am not really that keen.*

*She then arranged for me to have a demonstration with two different types and then for me to say which one I liked better and I remember having this conversation where I said if I had to pick it would be this one but I don't really want either because I don't see when I would use it!*

*Then it just turned up and I was like oh, they bought it anyway, yeah, great.*

The enforced homogenisation that Emily experiences here highlights the ways in which assumptions are made about individual VI and disabled students on the basis of constructed stereotypes and draws comparisons with that which William and Georgia experienced. Despite Emily expressing her unwillingness to use a technological aid that she was unhappy with, the assessor overrode her individual assertions, instead responding to an assumed need based on their construction of visual impairment and visually impaired students. This aligns with Michalko's discussion around the use of assistive technology in his own experience, stating that "in the midst of this sweepingly smooth and milky sweet fog of sameness lurks the figure of difference" (2002, p.80). The addition of assistive technology which premises a degree of sameness, of levelling the playing field, instead predicates difference.

Emily's expression of her autonomous view, based on her experiences, is dismissed and thus Emily was also positioned as incapable of making decisions about her own requirements and preferences. Such conceptualisations maintain traditional, negative, assumptions about disability and are a constant theme throughout the retelling of the participant's experiences. In this case, Emily's experience also may be related to the common misconception that visually impaired and blind people are usually Braille users, although this is often not the case. For those who did not attend earlier statutory education as a visually impaired child, which would enable familiarity with Braille, there is little opportunity to engage with and learn Braille as an adult. In addition, this requires access to the limited course providers of Braille training. Further, not everyone would will even want to learn Braille given technological advancements such as those associated with smart phones and accessible software. In Emily's case a dominant construction and discourse may have underpinned why her lived experience was dismissed. Additionally, for Emily, that "doing things technologically differently from others is now represented as the key solution to the problem of blindness" (Michalko, 2002, p.81) the provision of equipment regardless of interest in it must be a reasonable adjustment and "we would no longer be on the thresholds of participation in society, we would be participants" (ibid).

Powerlessness and the construction of the visually impaired student as in deficit did not, however, emerge in all accounts, reflecting differences across the sector, but also differing constructions of the student. For example, Luke felt he retained a degree of power within the assessment process and so obtained the equipment that he felt he needed.

*Where I did have a fairly positive experience, was with ...the DSA experience... the guy that I was working at the time was good and I was able to write out a bit of shopping list and just tell him what I need and why and all the funding was in place before I started.*

*I don't know, maybe it was that this guy didn't know and looked towards me for guidance!*

Luke's account of the assessment process is more positive. He positions the interaction as a collaboration between him and the assessor, noting that he thought the assessor was unsure of his needs. It may have been that Luke's age made a difference, as he was a much older person than Georgia, Emily and William. In a sense, in their cases, the intersection of youth with VI may have had an impact upon the way they were treated. Luke's account shows more inclusivity than theirs, which labelled them as the passive receiver of a common-sense approach. However, that Luke was still required to undergo an assessment to get access to equipment again shows how the construction of the visually impaired student within HE is imbued with dependence. Luke still experiences as a mature student, similarly to his younger counterparts in this research, the imposition of infantilization onto disabled people (Slater, 2012) which positions him as in need of help.

Luke holds a relatively unique position amongst the participants, as he was able to ensure he received the equipment and resources that he preferred. However, there were other experiences that were not so positive. For example, he noted that in terms of other methods to ensure he was able to access the curriculum, such as having recordings of lectures and access to learning resources such as course content, PowerPoints and so forth, this was often not forthcoming. He required information to be made available prior to the lectures, preferably on a disc and this did not occur, leaving him frustrated and consistently 'playing catch up'. This suggests that there were two very different constructions regarding support in tension within the institution to the detriment of Luke as student, pointing to issues of inconsistency of provision not only across HE, but within individual institutions.

## The influence of 'special education'

Drawing again on Michalko's discussion around 'special education' and the link with rehabilitative processes (2002) Georgia's acceptance of this process of allocation of support as part of her identity as a disabled student suggests that it may have become ingrained from an earlier age. This reflects that she was visually impaired across earlier life and so had an identity as a disabled school pupil. Georgia's hereditary visual impairment, which she explains has been present since birth and changed considerably in her earlier years, means that her experience of school education has become interwoven with her expectations of higher education, informing how she approaches it.

Accordingly, Georgia expects to grow through the DSA process regarding HE, which chimes with the accounts of other participants in relation to higher education and their prior experiences in education, depending on their life experience of VI. The acceptance of involvement with support services and assessments indicates the importance of understanding how the earlier lives of visually impaired students influences their current and future experiences. For Georgia, involvement is a natural part of recognition as a disabled student, thus necessitating taking on board many constructions of disability. Georgia's experiences in statutory education afford some clues towards the ways in which earlier educational experiences can and do influence higher educational expectations:

*I had a good experience really with the university. A whole lot better than school I found, especially sixth form.*

*I went to a school that had a VI unit and you had people in your classes, like, I had people [support workers] in my science classes mainly for practical tasks, reading the board.*

*When I got to sixth form they were like oh, no, you have to be independent now and we are not going to put anybody in your class; so that was a bit of an oh, ok, fair enough moment, quite an odd way to phrase it!*



*So, I didn't get much help from sixth form.*

Georgia here discusses her experience at university positively against the backdrop of a statutory education that did not always fulfil her expectations. The construction of independence here as forced and coercive is particularly significant in relation to that institution's construction of age. This intersection of transitions around age with VI leads here to the former being dominant, an ableist construction based on social traditions. Irrespective of the actual needs of individuals, certain transitions trigger enforcement of behaviour based on assumed norms.

As Slater (2012) discusses, education, disabled youths and childhoods are often at the crux of normative timeframes, which, by their site within educational classrooms, are weighed upon by developmentally sited constructions of the child and ability in relation to time, age and stage. Georgia, as a sixth form student studying 'A' Levels, was expected to take on a role as an independent, autonomous learner, outside of the reliance of support that even a few weeks or months prior was considered necessary to her educational experience.

Georgia identifies similarities with her university experiences, in particular the ways in which decisions were made outside of her control, yet, the assumption after DSA of the need for a support worker at university showed a similar level of expectation about her as within her earlier statutory education, restoring some kind of continuity. This continuity could be read positively, but also as a sign of what Slater (2012, p.195) suggests is the infantilising of disabled people, the "positioning as forever young". Why sixth form did not expect this reliance, in contrast to her other educational experiences including HE, cannot be fully explained without talking to school staff. However, in terms of the ways in which disabled young people are expected to reach a position of adulthood from a developmental approach to childhood, perhaps simply attendance at this level brought with it an expectation

that Georgia had reached the final stage of youth prior to adulthood. As such, she was thus required to take on an autonomous role, in control of her own educational achievement and participation.

### **Accessing higher education as a visually impaired student.**

#### **Accommodation: access to spaces and places**

Across the range of participants there were varying modes of accommodation; some lived in the family home, whilst others lived with friends or in university halls of residences or other university owned accommodation. For those who lived in on campus there were several common occurrences shared by participants. To begin with a little description, types of accommodation reported by the participants varied from a room within shared flats to single self-contained flats. Some were specifically made accessible for disabled students. There was no key similarity between all these places, nor were there differences regarding experience of accommodation dependent on the gender or age of the participant. This appears to be similar to the ways in which the student population, as a whole, has engaged, over generations of students, with university accommodation.

Georgia was allocated accommodation in halls of residence, with her partner, in accommodation specifically designed for disabled students:

*There were two flats, one lad next door, he was a wheelchair user. It was a one bedroomed flat, with a living room and a dining room and a fairly big kitchen. We made it quite accessible in terms of putting tactile things on the cooker as my partner was registered blind. It also had a lift, so the university had made it accessible in that way too. There was a warden and a cleaner in there and they got to know us quite well, so they would keep an eye on us, reminding me that I had left the washing in the washing machine.*

*Plus, it was really accessible for us. It used to take 10 minutes to get round the campus and there was a shop right next door too... the advisor showed us round the accessible accommodation when we came for open day so we could make a choice.*

Georgia discusses here the ways in which accommodation was deemed suitable for her and her partner's specific requirements, noting the need for an accessible flat for her partner. Yet she also describes the modifications they had to make to it to ensure that it was suitable. This represents their agency, but also indicates limitations in the provision. Whilst Georgia was initially satisfied with the accommodation, that staff would "*keep an eye on us*" suggests several possible readings. On the one hand it implies a degree of acceptance, community and a possible protectiveness, on the other, an assumption by the staff, reflecting a construction of VI that Georgia and her partner had a limited capability to cope with living independently, so constructing them as in deficit. Borland and James (1999) in their examination of a single case study university and the experiences of disabled students at that institution note that the ingrained reliance on the medical model which remained present, despite adherence to a social model perspective, continuously created tension at the heart of provision of accommodation, something also evident here. Accommodation services within an HEI then, also seemingly assume that they know best what a student's needs are, again emphasising a paradigm within HE regarding VI that is in tension with the lived experience of VI.

This near tokenistic provision of disabled student accommodation in amongst a large student housing residence indicates that expectations about disabled students may have remained consistent despite the long period of time between Borland and James' research and Georgia's experience over a decade later. However, the HEI had at least provided accommodation that was broadly appropriate and consulted with her and her partner. This contrasts with the experience Naomi shares in relation to her accommodation on campus:

*I asked to be put in halls (of residence), nothing special and because I am visually impaired I assumed that they would put me somewhere sensible.*

*They put me somewhere outside of the campus, down a road, where bits had boulders and potholes in. It was all gravel, there was no lighting, and it was pitch black, and I was the end house!*

*My bedroom was at the top of the stairs, like literally near the step, where you would walk down. It was like the least blind friendly place, ever!*

Naomi requested accessible accommodation in terms of being well lit and relatively easy to physically access. For Naomi here, and Georgia previously, having to demand specific and individual access further positions them as different, and is indicative of the ways in which as visually impaired students they are made to be 'other' by the tension of normal/abnormal; able/disabled. This additionally reinforces the expectation of normalcy that underlies participation in higher education; to be involved, even at the level of accommodation requires the capacity to conform to the everyday and the norm.

Naomi's comments highlight a lack of understanding about how addressing specific requirements can encourage a sense of belonging to the university. As indicated, Naomi's expectations about what she deems suitable, and what the university does, are different. This alerts us to the ways in which access and participation often appear tokenistic and as an afterthought. Whilst it is clear that social model thinking can help to reveal the structural barriers that deny participation, what Naomi's comments show here are the underpinning ableist ideals that pervade daily life.

Her comments also reveal her initial perspective that the university would understand what she considered 'sensible' flagging up problems with communication with accommodation staff, as is also mentioned in Bishop and Rhind, (2011). This is suggestive of a construction of the university as a place where the access requirements of visually impaired students might be met. Her comments

have expectations have embedded within them that reveal an assumption that, as a student and a person, her needs and rights will be fulfilled. In many respects this is a natural progression likely arising from an awareness of the existence of the breadth of access legislation that has aimed to break down the structural barriers that have precluded disabled people from accessing environments.

However, the attempted removal of the barriers that exclude disabled people from environments does not mean that concurrently procedural obstructions will also be removed. As Naomi's interview shows, where the requirements of impairment are not taken on board, access issues remain, so that whilst Naomi was figuratively able to access her accommodation, in practice she struggled with the environment. This is, to an extent confirmed by Bishop and Rhind, (2011, p.186) when they describe that one of their participants described an incident in their supposedly suitable accommodation, that "she had fallen over in her room because of insufficient lighting and awkward furniture layout". Titchkosky notes that access issues can arise for anyone and at any time, not just relating to disability, and Naomi's issues with the environment concur with Titchkosky's assertion that the "conflation between the radical diversity of embodiment and the single iconic figure of the wheelchair user" (2011, p81) means that access is often reduced to adjustments that focus on the removal of physical barriers such as placing ramps or displaying disabled 'friendly' signage.

In Georgia's account, that these were the only two flats for disabled students, allows discussion about adjustments that have been made in the name of providing inclusive spaces and participation as a practice. The number shows a minimalistic approach that may be underpinned by a wider perception of higher education as beyond the capacity of disabled people. Of course, this limited number can also be read as efficiency in economic terms, as empty space would not be profitable, but

making all the flats have a good level of accessibility would be genuinely inclusive. Whilst recognising that there is a degree of cost associated with the improvement of the accommodation, it is necessary for universities to make reasonable adjustments which promote the access rights of disabled students. As is shown with the Disabled Students (2017, DSSGR) advisory report into inclusive education within higher education, what a reasonable adjustment is can be dependent on a number of factors and ultimately may require legal intervention, as it argues that what is reasonableness regarding adjustments is for courts to decide.

This tension between what an HEI is willing to offer, and what might be best practice for all students, is a clear indicator of the ambiguity that surrounds what a reasonable adjustment may constitute. As Georgia's account showed, adjustments positioned as for the benefit of disabled students that take a homogenous approach are likely to be too generalised and as such may not be the best use of resources, whilst an environment which is adaptable could be beneficial. As budgetary constraints are increasingly affecting resources, alongside the responsibility which lies with universities to implement reasonable and anticipatory adjustments (UK Equality Act, 2010) closer examination on the part of HEIs of what should and will be provided would be useful. Georgia does show us that in her experience she views the role of the university as collaborative, not excluding. Where she and her partner had attempted to make the accommodation accessible and suited to their requirements, she compared this to what the institution had done regarding larger structural aspects by which '*the uni had made it accessible too*'.

However, the larger structural aspects may in themselves be problematic if their development is not directly influenced by disabled students. The structure of the accommodation was perceived as suitable, but only in relation to the iconic figure of the wheelchair user as the universal image that explains and legislates for

disability (Titchkosky, 2001, p.81) and so shows limited understanding of visual impairment. This iconic figure appears to us in Georgia's comments as the user of the lift, the neighbour in the other accessible flat. Georgia identifies herself as 'other' to the neighbour, recognising, as noted earlier, that the accessibility provided was not specific enough, and that she and her partner made it "quite accessible" by adding tactile stickers and raised dots to equipment.

In addition, when Georgia speaks of further adapting the space, this also implies that the original flat was built with a generic disabled person in mind, the 'one-size-fits-all' approach, again drawing on image of the iconic wheelchair. Georgia's experience suggests what Titchkosky (2011, pp.76-77) argued about the "harsh paradox of the inaccessible labelled accessible". From the outset, from approaching the university as a prospective student, presupposed ideas about the needs of disabled students and constructions of VI students are prevalent. Access takes more forms than physical exclusion from geographical locations, although that is one aspect of her account. Pre-allocating Georgia accessible accommodation suggests an assumption about the philosophical and geographical spaces disabled people can and should occupy.

Creating accessible accommodation solely designed for disabled students, alongside those occupied by non-disabled students, places disability within a bounded space and positioned on the fringes of participation. As Michalko (2002, p.129) notes where accommodation (in its most general term) is made for disabled people it is often "reluctantly under the yoke of some legislation". He further suggests that where accommodation is made, this does not represent "transformation of their environment into ours. Instead they represent what is required to accommodate lack" (ibid). This highlights the liminal experience of being a disabled, VI student, thus occupying two spaces, firstly that of the disabled student

and the presuppositions brought about by that identity within HE, and secondly, one of alongside existing on the fringes of an ableist heteronormative construction within HE of who can be a student. As noted, the provision of two student flats that are specifically for disabled students, in that one block, suggests an inherent expectation that disabled students are less likely to attend university. Whilst there is much evidence that the numbers of disabled students are significantly smaller than those who do not identify as disabled (HESA, 2014), this leads us to question whether this is in some part due to such aspects as the provision of less 'disabled' space which thus reinforces the message that disability is a problem and is therefore less welcome.

Additionally, whilst it is clear that Georgia felt that her accommodation was suitable in terms of her analysis around the needs of her and her partner, what the lack of accessibility elsewhere also suggests is that disabled students would not be able to mix socially with other students, even when living in the same building. This implies an organisational construction of disabled students as outsiders. This is similar to the findings of van Jaarsveldt and Ndeya-Ndereya (2015, p.210) who noted that language used by participants in their study of disabled students was "laden with exclusion" and separated disabled and non-disabled students as in and out-groups. Georgia's experiences here show how the simplest adjustments can mean there is the potential for her experience as a disabled student to be inclusive, sharing space with other students, yet overall there appears an implication that she and her partner must fit into the space that the university has delineated to be suitable again reinforcing the ideals of an ableist society.

### **Shared space?**

To continue my focus on accommodation, but moving on to shared provision, both Maddie and Peter's accounts discuss their experiences of this in university.



Their accounts highlight a significant gap between practice and the rhetoric of participation.

Maddie's narrative focuses on her experience of moving into a shared flat in her first year at university with peers that she did not know. Maddie had already experienced living away from home, having spent time before coming to university working and living in another country. Here she shares her experiences regarding the shared spaces of the university accommodation:

*I was very keen to be nice and friendly but they [her housemates] just didn't really... they didn't know about blindness; I was obviously the first blind person they had met.*

*They could never ask questions though; I always started by being friendly and tried to say just ask me questions!*

*I would say things like you know, if I have been cooking and have made a mess of the kitchen I am not meaning to be messy, but I cannot see the mess, please just tell me and I would always clean up after myself; but I saw it more as a please open that dialogue with me.*

*Anyway, one day I did make a bit of a mess and one of the girls I asked to check the kitchen said, 'oh, it's fine it's clean and everything' and then I left the kitchen. The other girls were like "OH MY GOD, you are so disgusting, you have made a mess and you are so lazy and so disgusting". I was like do you want me to clean it and they were like, no we are doing it now. They went and put it on social media. I was horrified.*

As Maddie explained this it was clear that she had been distressed by the experience, and revisiting it had acted as a trigger, so I offered to give her some time to compose herself. When I asked her how the incident was dealt with, she continued:

*I talked to the disability department about it but they, well, were not that great! They did suggest getting someone in to do some visual awareness training... we all moved out before anything happened.*

Maddie's account shows how upsetting she found this event in terms of the reaction of her housemates but also of the university. Whilst only a single incident it represents both a flash point and acts as a summary of her experience of shared living. In addition, this account shows that an inherent negative construction of

disability and a prejudicial attitude can remain at both individual and institutional level. In effect, the actions of peers, intended to expel Maddie, indicate their belief that she is not a student in the sense that they feel themselves to be, another construction of the VI student as lesser.

Maddie's experience represents a missed opportunity to develop cohesion amongst a diverse student group on the part of the individuals and the university. The university could have dealt with this in a way that developed her peers' knowledge of how Maddie experiences her visual impairment in terms of living arrangements. Additionally, and more importantly for Maddie herself, the excessive response she reports is, simply, bullying. The institution only latterly recognised that it could develop a better understanding amongst the student cohort and came to a perhaps overly simplistic, reactive, response to the situation by offering awareness training to her flat mates. Maddie's experience shows similarities with the findings of research conducted by Lourens and Swartz (2016, p.248) who similarly found that the visually impaired participants in their research experienced "shame and exclusion [which] pointed to isolation and the intolerance of difference" in their interactions in their worlds. Visually impaired students, like other disabled students experience their participation as on the periphery due to the ableist constructions of the idealised student.

Worryingly, in terms of the legislative and policy discourses of the Equality Act (2010) this was also a missed opportunity for the support services which were positioned to arrange and manage the overarching aspects of student life to ensure that none of the practices which Maddie experienced were disabling. For example, if, as is argued by the Disabled Students Sector Leadership Group, many institutions already engage a social model perspective (DSSLG, 2017), then there is a clear need to draw out and encourage better understanding of what this looks like in terms

of procedures and practices. To cast a “critical gaze to university policy and practices” which despite legislative and policy directives which draw upon equality and diversity, “still fail to make their environments accessible” (Lourens and Swartz, 2016, p.248) is to cast a critical gaze over the underpinning notions about disability in HE which these policies and legislative positions are built upon.

This means that it is important that universities work with all departments, students, colleagues and other universities to identify and tackle barriers to participation. This is a point where the intersection of higher education and visual impairment as constructions reveal a very significant rupture, a clash between paradigms, although the use of the social model ought to counter this. However, what is being experienced here is typically a simplistic reliance on the social model by the institution to explain all aspects of disability, something that highlights the limitations of the social model. In terms of Maddie’s experiences, simply engaging with the social model to challenge disabling barriers would not challenge the inherent attitudes towards disability shown in her interactions with her housemates. Instead, policies and materials dealing with inherent ableist ideals about personhood may offer both a better analysis of why exclusion was the result and possible ways forward regarding unsettling and destabilising excluding views and ideals

The limitations of institutions and bias of individuals also featured in Peter’s recounting of his experience of shared accommodation. Peter’s account highlights that a similar situation regarding bullying behaviour developed within his second year in halls. Peter felt that his flat mates were intimidating him and attempting to drive him away, a rejection based on their construction of VI. In particular, students in his shared accommodation would leave out items that could cause him potential harm:

*They were pretty weird about the whole thing. They sort of determined that they shouldn't be told how to behave and that includes being considerate of other people, so basically, yeah, they used to leave out stuff. Like, one of them left the iron out in front of the microwave and it was still hot; someone else had left a tin opened and all the sharp serrated edges were just here on the side and you know, when people sort of asked them to look at it, they went on the defensive and said stuff like we weren't told we were living with a blind person, we should have been warned!*

Peter highlights here that there were continually microaggressive incidents. Examining these as part of a wider discussion around the ways in which he was viewed by his peers shows inherently ableist underpinnings in the attitudes of the housemates. This may reflect that, as Goodley (2014, p.41) argues, “children are imbued with the neoliberal ambitions of parents, teachers, and governments”. Taking neoliberalism as an ableist endeavour, (Goodley, 2014), the expectations about disability are clear, as is the insistence that this is a place where only normative constructions of the body are welcomed. Further, as Michalko argued, “Society forces disabled people to conceive of, and subsequently experience their disabilities as the unfortunate expression of biology gone wrong and thus to experience an isolated form of suffering located strictly in the individual. It becomes extremely difficult, if not virtually impossible, to experience suffering as a collective or intersubjective matter” (Michalko, 2002, p.61). Peter here is positioned externally to his housemates, as Maddie was previously. The ableism that welcomes ‘smooth personhood’ and ‘working bodies’, is evident in Peter’s experience here, and in the experiences of others. It is also explicit, for as he reported, the students themselves said: “*we weren't told we were living with a blind person, we should have been warned!*”.

Impairment when positioned in this way remains a private trouble, its existence embodied within individuals like Peter and Maddie. The reactions of their flat mates to the existence of disability in shared accommodation in an HEI highlights

how, despite the attempts to alter attitudinal and individual responses to disabled people, internalised prejudice about impairment remains. Peter and Maddie's presence brought the question of impairment into the open and the negative connotations associated with disability brought about a response that rejects individual disabled people and, more broadly, disability. The presence of the VI student, their visibility, troubles their peers' constructions of disability, and their attempts to 'un-see' involve severe responses.

The university responses to the situation also indicate problematic perspectives within HE regarding VI, again bringing the two into tension. This is particularly evident in Peter's account when he exclaims:

*They wrote a letter to the next group, that's what they [the university] did! So, the uni pre-warned the next group! It wouldn't have changed who they were, not in the slightest, they may have just decided not to live there, that could have been what would have happened.*

Peter's narrative suggests that the ableist constructions that he had alluded to previously were foregrounded by the university placing an obviously greater value on the experiences of the cohort of students that were due to be moving in to the shared flat with Peter, than on Peter's experience. Here, the university took a stance which promoted the idealist notion of the abled-body over Peter's position within the university by overtly identifying him as a visually impaired student. Peter's account reveals an obvious and understandable frustration with the institutional assumption that his visual impairment merited a process of pre-warning potential flatmates, bringing with it an implied assertion that those who were to live with Peter were expected to manage a 'non-normal' living arrangement. Furthermore, Peter was only made aware of the institution's actions when a housemate informed him, after questioning him about what must have occurred previously to necessitate it. This lack of consultation suggests a view of Peter as an abstract problem, a construction,

a hypothetical blind man rather than a person. The implication is that the construction of the visually impaired student requires special attention in order to manage the problem of impairment, and that the impairment is more significant than the person.

As Michalko (2009 p.66) suggests when disability appears, and appears as a troubling thing, it appears “both in our presence and our absence”. In Peter’s account he appears, when he does so, as both as troubled and troubler. The two are inseparably linked and are there both when he is present and when he is absent. As Michalko stated, “Blindness, for example, makes an appearance, is made to appear, as a troubling thing, as a thing that is trouble... blindness appears to and for me as trouble, and *now I have trouble*... but, interestingly enough, so do you.” (2009, p.67) [original emphasis]. By positioning Peter as troublesome, by the HEI accommodation service contacting potential flatmates to make them aware of the existence of disability within their flat, Peter has become represented as the passive embodied hypothetical blind man.

Participants do talk about their experiences as passive subjects of ableist and disablist constructions and actions. For instance, Peter was acutely aware of how he was being represented by and to others, in part because of his youthful appearance, but more specifically because he has visual impairment:

*I am always under scrutiny perhaps and people make assumptions, what I have is that I have a number of things going on; I look young therefore I get mothered! Whether I like it or not, I am not very tall and these all get combined, and maybe make it worse. I know it cannot just be me, it has to be the disability.*

Peter’s articulation of his embodiment of a number of ableist, non-normative assumptions and his account of intersectionality regarding age, represents a key point. Like the other accounts regarding accommodation, where it might seem

unlikely that such a subject would appear, Peter's highlights the appearance of disability. Again, drawing upon Michalko's (2009, p.66) depiction of the appearance of disability where "disability appears as a thing that troubles our lives", it troubles Peter's life as he experiences reactions towards his impairment as a result of the actions of the university.

Peter's account of his experience draws heavily on the notion of the double bind as posited by Titchkosky (2003, p.75). Where this double bind is a guiding principle in sighted and non-sighted interactions by "offering blindness up as an object for discussion while obliterating any subjective interactional consciousness of blindness", it offers up Peter's experience of blindness for discussion by the university with others who may participate in Peter's student experience, whilst failing to engage with Peter. Yet this "interactional event, out there" is inconsequential for all except Peter. How Peter experiences his impairment, how he feels about having this information shared, or that he has had this subject position enforced upon him by the actions of those who yield power, is insignificant for all but Peter.

As Titchkosky helpfully explores blindness is something "out there", something outside of most people's daily experiences and knowledge and which can be a point of discussion, to be made note of and agreed upon as different, yet this is where the interaction ends. These accounts confirm that this is the case. For example, Peter embodies blindness to the university and his potential flatmates, which shows clearly how constructions about blindness are developed, held on to and disseminated. Blindness is the operational tool with which to discuss participation, involvement, disability, yet it ends with that abstract discussion, not with change, nor with engagement with individuals. These participants still face challenging ableist attitudes and assumptions about their participation within their

places of study, or even the accommodation related to that study. They, as students, are not afforded autonomy, choice and recognition as participating students in their own right.

For Titchkosky (2003) the environment which does not anticipate for disability is based around an assumption of the abled body. This appears to resonate with the participants comments about their experiences of accommodation. As Georgia, Peter, Naomi and Maddie have shown here, their experiences of accommodation all highlight an underlying tension between the expectations which surround constructions of visual impairment and the reality of accommodation at university.

### **Inaccessible spaces**

#### **Learning environment**

There are other issues surrounding accommodation, something that Naomi particularly flagged up in her account. Whilst she mentioned the flat itself as problematic, her main concern was about the relationship of this accommodation with the campus more generally, and so touched upon spatial and geographical issues about the university. Naomi remained frustrated and, at times, angry, due to the accommodation issues she experienced all the way through her course:

*I spent a whole year in that flat, down the lane, in the dark, with the potholes. Thing is I had met with them and said somewhere with good light, you know? Nothing special, relatively easy to access would be good. As soon as you came out of my room, to your immediate right, there was a flight of stairs and no lighting!*

*The second year they put me in a really unsuitable place, where most people had severe mental health issues, they must have thought oh here are these problem people, we will just put them all together.*

*Finally, they agreed, and I was able to move in with my mates... even then it wasn't the best as I still had to learn routes, but I was on the bottom floor and under a streetlamp, so I could find the door!*



Issues about space around the campus compounded Naomi's issues about space within flats. This is also identified in Bishop and Rhind (2011, p.184), who mention the concept of "campus navigability" stating that in their single campus study "mobility around campus was not hugely problematic for this group of students; however, this may have been more a result of their determination than of the university's consideration". Naomi's account states that the location of her accommodation was unsuitable given that the terrain was dangerous, showing a similar determination regarding navigability, and, indeed, in persisting with study given that journeying across campus remained problematic throughout the first two years of her course. She also indicates a homogenisation of disability in terms of accommodation by the service within the HEI.

She also commented upon changes of location regarding lectures and seminars, a different issue but still requiring the negotiation of campus spaces. Naomi's interview indicates that room changes may pose difficulties regarding navigability, explaining that problems were exacerbated by the way in which changes were not communicated to her successfully or within enough time to allow her to find the alternative room that had been allocated:

*A lot of the universities are so old, so the locations are random... you know if you are visually impaired and you need to learn routes yet there would be so many times where they changed rooms or changed it to a random building like halfway through the day, or the day before.*

*It meant that, I, even if I didn't have any friends in that lecture, would have to find random people on social media and ask, "can I come with you", even if you have never met them before! It was so bad.*

Naomi clearly navigates the campus confidently, but this experience still reveals a lack of inclusive practices and a construction of the VI student's needs as insignificant. Support via the DSA for study is positioned as vital for access, yet simultaneously HE constructs the VI student as capable in all other ways, again

suggesting a token support and limited understanding overall. Accounts of other aspects of student life are therefore needed, as in this thesis, to increase understanding and so, participation. In terms of promotion of a learning environment that is suited to all learners, a truly inclusive environment, practices that benefit the whole community are needed. This case, in contrast, shows the institutional promotion, even if unintentional, of a construction of ableism whereby the assumption is of normative able students and disregards Naomi. Naomi, as other students would, requires information in a timely format when rooms are changed. Naomi's experience shows similarities with the small number of other studies into this area, whereby simply navigating the physical campus can be tricky without the additional stress of new routes or places, especially where these are not communicated in a timely and inclusive manner. These access issues are not solely limited to VI students, but also those with caring responsibilities, those with anxiety and students with limited mobility. In all cases, the overall construction of HE around a hypothetical 'ideal student' serves to position these groups as other and so their construction is in tension with that of the institution.

I draw upon the work of Titchkosky (2011, p.81) here, again highlighting the "iconic figure of the wheelchair user", to unpick the underlying assumptions about the ways in which accessibility is considered and constructed within practices. Naomi's reliance on others to help her negotiate room changes positions her within her student cohort as a student perceived as in need of help or support in order to successfully navigate the environment and community. This again signals that the construction of the VI student and that of HE are in tension. Within this there is a construction of a single problematic figure, who may be, as Michalko (2009, p.74) suggests, through the process of rehabilitation and/or special education a "body that disappears, drowns and dissolves into the single social whole of all bodies". This

absorption removes the “excesses of disability” from visibility, removing difference and as Michalko (2009, p.74) summarises:

All that is lacking does disappear, but so too does any opportunity to engage with the disabled body as an occasion to theorize and to re-move ‘normalcy’ to the place to ‘think with’ rather than a thing to ‘thoughtlessly be’.

Michalko’s summary suggests that this process of overlooking the excesses of disability takes away the opportunity to challenge conceptions of normalcy and ableism inherent within the experience of being disabled. To examine and think with the participants’ experiences, then, helps to illuminate the thoughtlessness of normalcy and the ways in which this excludes visually impaired student’s participation.

Participation is not just the physical act of being on campus, it is the preceding and following assumptions that are made about the spaces that visually impaired students should inhabit within the campus. Whilst there have been overt attempts, such as those of Maddie’s and Peter’s housemates to push impairment to the fringes of their student lives, little of this would appear as obviously the result of university policies. Yet when unpacking this further it reveals the underlying constructions which inform and instruct the practices and procedures, and which are meant to provide welcoming and inclusive spaces for visually impaired students.

The alikeness of impairment (Michalko, 2009; Goodley, 2014) draws out this concept of similarity which influences the ways in which people react and act towards impairment and brings with it a misconception that all disabled people require the same physical alterations to an environment in order to partake of what is offered within it. What Maddie, Naomi and Peter’s accounts show is that it is not impairment that is alike, it is the alikeness of ableism that is apparent, and which

informs understandings of and about disability and, particularly here, visual impairment.

Inaccessibility may simply be judged as a lack of forethought; however, this may be much more complex in what it reveals about underlying conceptions regarding disabled students. Questioning whether to be a disabled student requires specialised interventions may be valid, but the removal of interventions in response to a perceived requirement to treat disabled people as if they are no different illuminates the tensions apparent within the conflation of higher education and the visually impaired student. By removing from a critical gaze any perceived or actual differences and thus any solutions, theoretical or practical, the sameness of personhood outweighs the importance of having suitable access, timely communications and an environment that can fit the requirements of the diverse student population likely found in a university. Inaccessibility, then, may be attached to the construction of higher education and the related construction of the organisational user, not simply 'just' about access to buildings or teaching spaces.

In conclusion, the overarching construction in HE of the visually impaired student is one that draws from common misconceptions about visual impairment and visually impaired people, as is shown by the stories shared by the research participants. As indicated by the discussion here, ableist conceptions about visual impairment remain strongly embedded in the experience of visually impaired students regarding physical space, accommodation, navigation, and a range of other issues.

Central, however, is that decision-making choices are removed from the individual on the basis that expert knowledge can provide the best solutions for each participant. For all the participants, the ways in which access to resources is withheld by others until they have undertaken an assessment that is overseen by

an expert shows how dominant medicalised discourses are prevalent in the experience of becoming a student. As Michalko helpfully sums up (2002, p.163) “The provision of existing technology to disabled students is one thing, challenging the inequitable and discriminatory character of such provision is another”. This chapter shows how, for each participant, the experience of being visually impaired in university does share similarities with those of other VI students across a number of HEIs.

## **Chapter Five: Support and Services**

This chapter focuses down on interactions between the research participants and support services within higher education and how the constructions of VI intersect with HE in this context. These services and provisions are put in place in response to the DSA processes flagged up within the previous chapter. They include support services within university departments, which are given a number of different titles, as is shown in the participants' interviews. To avoid confusion, I group all of them under a summary title of disability support (DS).

I explore a number of relationships between the research participants and staff and students within the university, particularly disability support services and support staff, and the impact of support staff upon the experience of university. I also explore the ways in which academic staff interact with participants and refer throughout to how student peers are positioned in relation to participants. By doing so I will illuminate how the notion of ableism is at play within these relationships and examine the ways in which the research participants respond to the sometimes subtle, and often overt, actions and discussions involved in them.

Support services offer a range of mechanisms including wellbeing and counselling services for students experiencing a range of issues within and outside of their immediate academic experience. Typically, participants' accounts report difficulties managing their experiences with support services, even when things are going well in their studies and academic lives. More serious matters were brought up in interviews as well in relation to support services. In these latter cases, the participants who raised issues identified that these had a significant impact upon their experience of university.

I begin by discussing participants' interactions with the disability support services within their universities. I follow this by examining the roles of academic support workers, such as note-takers. Finally, I explore the participants' experiences of the attitudes of academic and support staff towards the specific needs of these students and how they were sometimes embedded in assumptions about the participants' assumed ability to study at university. These all illuminate the ways in which VI students' constructions of participation within the university environment are influenced by factors that are part of the various constructions of the generalized disabled or VI student by HE.

This chapter, overall, covers a range of issues and is particularly aimed at addressing the research questions: Is the experience of being a visually impaired student at university different from that of other students? How does the experience of being visually impaired in HE impact upon the individual? In what ways is the concept of participation played out in relation in accounts of the experience of visually impaired students in HE?

### **Disability Services**

The ways in which participants engaged with a range of support services varied, as the interviews indicate, but all participants did engage with DS teams. Other services engaged with, as noted in interviews, included, but were not limited to: library and academic support services; administrative services and estates and catering services. Interactions with both these and the specific DS teams proved sporadic for some participants, although for others, interactions with various parts of the support services were much more in depth. However, all the participants shared a common engagement with DS from the outset, following the initial Disabled Students Assessment process. For some students this formed the majority of their

contact with these services, but they were significant interactions from which some conclusions may be drawn.

For example, Maddie discusses her interactions with the support services at her institution in depth, having had many dealings with the university support teams. Maddie's interview states that her initial interactions with disability services were positive, leading her to believe that she was attending an institution which proactively sought to provide alternative formats, premising a level of participation and understanding of different requirements from the outset.

*When I visited the uni they impressed me, they were by far the best. I walked in and they gave me their prospectus in Braille, the disability department that is, and that was a massive plus. I am a massive Braille reader, so, that was great!*

As Maddie highlights here, her initial interactions show how the university portrayed themselves as a potential provider of services that were rooted in an inclusive, positive and disability aware ethos. HE was understood by Maddie as in line with her understanding of herself as VI and as potential VI student, meaning that they were, to her, matching constructions and paradigms. The provision of diverse formats for Maddie led her to believe that this initial interaction would be representative of the rest of her time at university.

The impact of the way in which universities initially portray themselves as an inclusive institution is a point recurring across participants' comments and appears in their detailing of their experiences. Indeed, this had a significant level of influence on the choice's participants made in choosing their place of study. Peter, for instance, had applied to a specific university after talking to their support department and finding that they were offering a level of participation and support that was relevant to his choice making.



Reluctantly, as I prefer not to employ labels to explain the experience of visually impaired students, I share here that Peter describes himself as totally blind, with no light or dark perception. As he explained, this meant, to him, that any institution would need to have a good level of accessible aids and understanding of what these meant for him as a student. His initial involvement with his chosen university highlighted a level that he felt was appropriate to his own standards and expectation. However, an external error in relation to his A-level marks meant seeking approval from another part of the university while waiting for an exam paper to be re-examined, before Peter was able to take up his offered place. Peter's experience of this other part of the university contrasted greatly with his initial experience. Peter said,

*The mess up with the grades, yeah, everyone knew that there was an issue and that it was getting re-marked and I told the man on the phone and he said it wasn't his problem and hung up! I didn't go to that uni after all that, even when my mark was put right. I had heard good things up until then too.*

This shows that when his impairment required additional contact, beyond that with the disability services, to ensure that he was confident that this enforced disruption would not impact upon his place at university, there were immediately issues which resulted in his curtailing his participation. In effect, he became aware of the bounded nature of his position, enmeshed within support services, but not, potentially, the rest of the university. His account shows the importance of disability support staff within the university and that the level of understanding that they are perceived to have, and offer is significant to the ways in which the potential student and the university interact. In addition, his account also brings about questions about the impact of disability support in marketing the university to potential students and how this can create the impression of a seemingly inclusive environment, something which can influence choice of institution. For these participants such organisational

factors were resoundingly influential on the choices and the experiences participants had. Therefore, it is crucial to understand the ways in which participants manage these interactions. How universities represent themselves to disabled students is interesting given that universities are increasingly modelling themselves on corporations, as Giroux argues (1999), and students thus are identified as consumers. The use of disability support as a marketing tool, for instance, has the potential to leave institutions open to litigation given the reported lack of support after individuals arrive as actual students.

Naomi's decision-making process was similarly influenced by her initial interactions with the support services within her chosen university. The advisor who originally met with Naomi initially seemed to have empathy regarding visual impairment. However, this was not borne out in her experience of university, as is evident when Naomi discusses the difference between her expectations and the adjustments made:

*When we went for my tour of the university we met the advisor and he was lovely, he was so helpful, and we thought he is going to understand... He was a nightmare in the end. None of it even happened.*

Emily experienced a similar pattern in discussing needs with support services before arrival and finding that there was a lack of consistency between the level of support that was said to be available and that which was eventually offered, suggesting 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 actually got there, very little of the support they had promised me was even put in place.*

What Peter, Emily, Naomi and Maddie experience here is an "it depends" factor whereby "[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" (Titchkosky, 2010, accessed 11/9/1). For Peter, the "it depends-ness" of his experiences and involvement in higher education was reliant on negotiating the bureaucratic processes at play within the wider education system. Arguably being dismissed in this way could have happened to any individual having to go through the process of having examinations re-marked, but for Peter to attend this university this was a final straw given the many other processes he had experienced that other students may well not have. In Peter's wider account, this experience of the process of re-marking is simply one example of the many bureaucratic processes that require him to depend on the HEI's preparedness to support his participation.

Other participant accounts were dominated by their negotiation of the bureaucracy at play within the higher education system. This can be seen as corresponding to the experiences discussed in the previous chapter regarding the identification of the requirements of individual students. This too adds an extra layer of processes for disabled students to navigate. Any support at university, then, draws heavily on understandings of disability as medicalised for students who, for instance, require additional physical support to access spaces, or engage with sighted support in the library, for example, in needing support to access written texts.

To return to the implications of the construction of student as consumer, disabled students, like their non-disabled peers, are increasingly are not just attending university to learn, they are buying a service or product, as discussed in earlier chapters. In effect, whilst universities are marketed as inclusive spaces offering products which are equally inclusive, disabled students are granted actual access to university based on a tacit understanding on the part of the institution that

to be part of the system requires a recognition that they are different, will experience additional processes, and thus should not expect the same consideration or levels of service as non-disabled students, another version of ableist normativity.

In addition, as Maddie discusses here, communication between university departments, and changes within them, can cause significant problems. As was the case with Peter, Maddie highlights that her choice of university was based in part on having support services she felt could best offer support appropriate to her requirements and whose perception of participation coincided with what it means for her. Whilst Peter had been disillusioned by interaction with other staff which ultimately led to him looking elsewhere prior to attending the university, however, Maddie found that changes in post had a direct impact on her experience on arrival as a student as the promised support appeared to be no longer available. This may be seen as reflecting an increasing lack of specialist administrative staff within institutions, something again possibly driven by the mirroring of corporate structures. Maddie highlights how the initial rhetoric of participation and differentiation displayed in her original contact with the university was not continued after changes within the department:

*Unfortunately, what happened, I later found out, was that I applied, deferred, and when I came back the department had changed. So, when I came back the nice 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.*

After deferring her university place for a year to take up a work placement abroad, Maddie arrived at university to begin her undergraduate studies to discover that the support she had been promised was not in place:

*I turned up for my lectures and all 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" and I was like oh, great...*

Despite Maddie's early involvement with the disability support team, her support needs were not disseminated to academic staff and so no pre-planning could take place. This was perhaps compounded by her year out and changes within the institution. Indeed, one may speculate that the consent form in this context may have been an initiative that was put in place after her initial application, although clearly there should have been some attempt to follow-up were this the case. All the same this was detrimental to her participation from the outset. Barriers were put in place that ultimately resulted in postponing completion for a year. Communication between parts of the university and the visually impaired student are problematic here, as whilst the support services had protected Maddie's privacy, they had seemingly not communicated what this meant, or what she would need to do, before she began study, to her detriment.

One element that might have an implication with regard to support services was noted by Hewett et al (2017). They argued in their recent research with visually impaired students and a small number of support service staff, that visually impaired students with a 'severe' visual impairment felt that the ways in which they experience interactions with the support staff differed to that of students with less significant visual impairment. Participants explain this as being due to reactions and actions towards them from members of staff, and one member of a disability support team stated that some staff felt "scared" when working with students with a significant visual impairment. The experiences of Maddie, Peter and Naomi concur with the findings of Hewett et al (2017) showing that, for the participants in both studies, the attitudes of the disability support services teams have impacted significantly on their choices in university. Ultimately this shows how the idea of participation can in itself actually be exclusionary as Graham and Slee (2008) suggest, particularly when teams subscribe to the idea that depictions of disability "represent disability as a

type that seems reasonable to exclude” (Titchkosky, 2010). As Naomi’s experience indicates, asking for even reasonable adjustments can be seen as problematic, even too demanding, by staff, and so rejected. As she commented:

*It is not like you are asking for the world... just reasonable adjustments to be made and no, nothing.*

This can be seen as reflecting what Stiker (1999, pp.150-151) discusses in his history of disability regarding the place within society for disability, whereby the experience of being impaired brings within it the need to be found a place, “[n]ot a place for sociability or a place of social networks but simply in society, in the social fact”. Maddie, Peter and Naomi, can therefore be understood to be challenging the conceptualisation of the space and place for impairment. Naomi asking for and expecting to have the benefit of reasonable adjustments, something enshrined in law, can be understood, through Stiker, as challenging the ‘place’ of impairment.

In relation to the expectation that disability must remain within its designated place within society (Stiker, 1999), Michalko (2002, p.149) discusses his ‘passing’ as a fully sighted person to illuminate the expectations of normalcy that are inherent in our interactions in relation to visual impairment:

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.

Hewett et al (2017) note the unpreparedness, albeit within a small sample of institutions, in how to make accommodations for visually impaired people. Also, Bishop and Rhind (2011, p.194) state, in their study of visually impaired students within a singular university, that the “greatest barrier of all may be the ingrained and

resistant attitudes of individuals both within and outside of HE” indicating that there are factors at play which Peter, and his peers, challenge.

These challenges and barriers created by others, as Michalko (2010, p.1) notes suggest how “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”. Peter, Naomi and Maddie have all revealed how, from the outset, that their interactions with the overall institution are constrained within existing conceptions of visual impairment and blindness, despite their rights, desires, and actions in working towards being present within the university (Titchkosky, 2010, accessed 11/9/18). Their accounts also indicate how their position as VI students has the potential to trouble and cause reflection within the HEI. This is related to what Michalko (2010, p.5) calls the “culture standard time” of blindness. This concept enables him to discuss how “[b]indness time, our time, is the time for sight, for normalcy, to develop self-understanding”. Michalko shows how, through the “mirrored shades” of blindness, that “in a world socially organized through and by some version of seeing” (Michalko, 2010, p.1) blindness reflects the social experience of difference dependent on the cultural representations, not only of blindness, which are present within “culture standard time” (ibid, p.1).

For these students, their early interactions with the university have created an image of participation that is underpinned by the perception of positivity towards disability and characterised by the proactive stance that appears in interactions with potential students. As universities further adopt a neoliberal agenda where the need to reach target regarding student numbers increasingly drives practice, then selling the university at this early stage is vital, which as noted, may prove problematic for the student/consumer on actual arrival. Some research participants referred to their awareness of this marketing aspect of the support services. As Georgia explains,

she was very aware of the need for the university to 'sell' their services to prospective students like herself.

*I can't fault the support services here, they were brilliant! I have heard some really horrid stories, so, I think I picked well. This was one of the reasons I picked this uni, was the support really was that good, really reassuring on the open days... It was really disability friendly for want of a better term...It was good that they did this on the open day, it does sell, and they do need to sell themselves. It is a big deal for someone that is disabled having that reassurance, it's a big deal.*

Georgia is clear that, to an extent, she maintains an altruistic expectation about the type of support that is 'sold' to disabled students where she comments "*It is a big deal for someone that is disabled, having that reassurance, it's a big deal*". Georgia's comments incorporate a discourse of higher education as a product, a consumable, and articulates here that disability support is an aspect of that product. It is also an advertisement in that it provides reassurance to the potential consumer that the university is keen to provide good quality services. For Georgia, this was crucial in her decision making about university.

Where Georgia feels that her experiences of the university generally and the specifically the support services within has been positive, other students have experienced this differently, as noted. Some students within this study report that there has been little support that is timely and appropriately effective. To give a specific example, Emily identified the support she required with learning routes around the campus, a process which is often managed with input from statutory services. However, this was not in place until around two months after the commencement of her degree programme and so not timely. This delay meant that Emily was reliant on a support worker to meet her and guide her to and from lectures and around the campus:

*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 around and*



*I couldn't do that; they couldn't arrange that mobility for me until November as it was going back and forth between uni 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.*

There is a duality present in the reliance on support services when making choices about education. Firstly, visually impaired students are often forced to be dependent, in many ways, on the support made available for them. This can include making the initial decisions about choice of university or course, liaising with academic staff to ensure that resources and information are adapted and accessible, arranging examinations, and providing support workers to work on a one-to-one basis with students. If the promised support proves inadequate or illusory, there is little recourse to address this, and students are again likely to experience education that is not inclusive. That such services may be a significant part of marketing to these groups of students can be read as cynical if there is no support, as promised, on arrival and this may be seen as indicative of negative constructions of visual impairment and disability by services within HE.

Secondly, students are typically unable to make choices about the types of support they receive as discussed earlier with regard to the DSA. They are unable, as is the case of the participants within this study, to challenge the provision if it is unsuitable. There is, in addition, limited information available about alternative methods of support, such as students employing their own choice of support worker. Finally, challenging the way DSAs are carried out, or the way in which support services offer provision based upon the outcomes of the DSA is similarly not possible. The construction of the visually impaired student here is emphatically that of an individual without rights, without a voice, rendered incapable and positioned as in deficit.

What this also suggests is that the flexibility often required by universities regarding staff, and their seeming interchangeability, is very much at odds with the specialist knowledge needed with regard to visual impairment and other students. This is further emphasized in interview, as when Maddie notes a clear lack of understanding about her visual impairment.

*So, basically, along with having to drop part of my degree because of the paperwork and the lack of resources, they didn't really know about my needs as a VI person.*

*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".*

That she refers to 'they' rather than a named individual and gives an example of a lack of understanding, shows staff anonymity, a barrier around awareness, and a lack of connection between students and staff. Maddie's choice of university was based on the significant level of participation she perceived as standard due to her initial interactions with the university, but her subsequent attendance illuminated a different reality. One way to explain what goes on in the interactions between support staff and students is through highlighting the tricky nature of disability support. It is important to incorporate this into thinking around this topic. Many of these students felt there was a disconnect between what was offered and what they needed. However, the role of support services staff is to fulfil their role in relation to both the student and the overall HEI. Consequently, committed staff operate in relation to potentially conflicting demands and, in particular, economic drivers that may encourage addressing needs in none-individually tailored ways. Indeed, what may be being identified here are the difficulties faced by everyone involved in delivering and participating in services.

## **Course Materials and access to resources**

To continue with Maddie's narrative about support, she was unable to access the required materials and course information relating to her course due to a lack of understanding on the part of staff regarding VI. She stated that:

*[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 and the assignments were getting nearer and nearer, so I had to drop part in my first year which meant I was that I was then a module behind to then pass the year. The university paid the cost of me doing the extra module, but it took me four years to do the degree.*

This meant that she was disadvantaged in terms of participation in comparison to non-disabled peers. This again raises questions regarding the inclusivity of the university environment and the construction of the disabled student within HE. Furthermore, this narrative suggests that 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'. Whilst Maddie felt that her original interactions with the university should have generated discussion and communication between academic and support departments to ensure that what Maddie was both entitled to and that which she required in order to engage with her course materials in the same way as her peers was actually delivered, the lack of communication excluded her so significantly that she was unable to sufficiently engage with the topic to the extent where she felt the only option was to withdraw from that particular route. The Equality Act (2010) requires HE providers to make reasonable adjustments that enable participation for disabled students, and there is clear evidence of some providers doing so (Hewett et al, 2017). However, as Maddie notes here their lack significantly affected her experience. Where HE providers are expected to make anticipatory adjustments

such as making sure course materials are suited to individual requirements, thus anticipating the requirements associated with being disabled, and associated with a specific individual's impairment, Maddie's examples show hers were ignored. As Hewett et al (2017) note, where anticipatory adjustments were not made this significantly impacted upon learning experience and participation.

Whilst Maddie's account shows that she is an autonomous student, what is illuminated here is the lack of communication, understanding and, also, again, a construction of disability that takes as its base a position of ableism. Maddie was given access in a tokenistic manner, by being able to attend lectures, for instance, but the lack of material in a suitable format combined with teaching that failed to encompass the differentiated ways in which people access information, proved exclusionary.

As Titchkosky (2000, p.197) suggests, when we examine the discourses of blindness or disability more generally, disabled people are positioned as unexpected and unintended people who are "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." Maddie's perceived inability to engage with information that is typically visual and the ways in which staff and students respond to this is discussed by Titchkosky (2000, p.207) who notes "Eyesight is the condition of normalcy, the expected, communicative, and yet non-obtrusive fact of normal life. Indeed, the "condition" of eyesight is only brought to awareness in the face of the conspicuousness of the blind," e.g., odd postures...and stigmatized paraphernalia that signifies blindness". Where Maddie can participate in terms of being granted access to lectures and the wider university system, when examining her experience of study through this concept of the conspicuousness of blindness it suggests why Maddie is, in fact, excluded from participating.

As Priestley (1998) contends, the collective social values which contribute to oppressive behaviours and actions do so in various ways, suggesting that these are manifested through the beliefs and attitudes of others and as such impact on disabled people's identity and experiences; or that these may be experienced on a large scale at a cultural or ideological level. Maddie's experience indicates that despite the legislative impetus regarding reasonable adjustments, underpinning this is a cultural expectation or value associated with visual impairment which contains, constricts and constrains those with impairment, an expectation "shared by groups of actors who have a great deal of power over disabled people's lives" (Priestley, 1998, p.87). Whilst there are policy and practices aimed at the promotion of participation of disabled people in higher education, what underpins and undermines this, often without being recognised, are inherent social values about disability and impairment.

### **Support workers**

In order to explore how support workers, influence the experiences of participants, I turn initially to Maddie's account, which highlights a number of potential tensions within this relationship. Like many other students, Maddie required one-to-one support to assist with specific tasks or elements within taught sessions. However, as her account reveals, being allocated a support worker can be confusing for the student if what the support worker has been told to do does not align with student needs. Maddie was provided with support workers described as note-takers, for instance, but as she used a Braille note-taking device in lectures that role was unnecessary. Her experience shows that there is a generalised label 'note-taker', and an accompanying set of assumptions about what that means. In her case, these assumptions resulted in a lack of effective support. Again, lack of communication was key. As Maddie states,

*They would allocate me support workers... whereas I take my own notes. 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.*

The expectations of the role on the part of the institution and so the construction of the VI student was, again, a homogenized one. That Maddie, who requires a very specific type of one-to-one support, repeatedly has to explain her needs to new support workers reinforces that there is a lack of understanding regarding inclusive practices within her learning environment. In Maddie's re-telling of her experiences she highlights the ways in which ableist assumptions surrounding disability and impairment are predominantly experienced.

Maddie offers further examples of the assumptions surrounding support workers, showing how the onus is on the VI student to manage the relationship. One aspect of support that Maddie required, for instance, was a sighted guide to help her locate a seat, or guide her in unfamiliar locations, such as new classrooms. She described the lack of communication between support services and students by saying,

*They gave me this support worker who was a student herself and she was lovely but really shy, so she turned up and said, "oh I'm here to take notes" and I tried to explain but I am not sure she understood. 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.*

The relationship Maddie describes here also highlights the lack of choice typically available. Maddie would have chosen a support worker familiar with guiding a visually impaired person but was not given the option. Nor was the support worker given appropriate training, suggesting a lack of communication, again, or economic drivers which limit training resources. Such generalised training and the assumptions that underpin it can have negative consequences for VI students given

that support relationships are likely to be complex, especially given these students' reliance on support to navigate new routes and spaces. If there is no specificity regarding what support is needed the relationship may fail to cohere, or the interactions could be very limited, so leading to tensions within the learning environment.

Furthermore, to be confident in the guiding skills of a sighted guide is crucial, as this does impact on the safety of the person being guided. The RNIB (2018) suggest that when guiding visually impaired people it is crucial to be aware of potential hazards, for example. Whilst this may seem a common-sense approach what may seem as a potential hazard to someone who is sighted may differ significantly for the visually impaired person. In terms of Maddie's experience and even though Maddie describes her as 'lovely', it is clear that the reluctance, or discomfort, of the support worker in guiding her became a source of tension. If Maddie had been able to insist upon having a note-taker with guiding skills, this would have been a more efficient use of resources for the institution as well as making the learning experience more secure. Taylor (2004), Douglas and Keil (2016) as cited by Hewett et al (2017) suggest that visually impaired students are often prepared to self-advocate (a concept discussed later in the thesis) in relation to their support requirements. However, in Hewett et al (2017, p.105), many students reported feeling unable to self-advocate in terms of "negotiating support packages; negotiating support arrangements; explaining VI and challenging if things go wrong". So, whilst Maddie is clear in her explanation of her expectations of the support workers role in interview with me, the use of the word 'gave' above, suggests both a lack of agency and limitations within the system regarding support suited to Maddie's requirements. Simultaneously, she is expected to take the lead in all aspects of her relationship with any support worker, so is seen as both competent

and incompetent, agentic and incapable of agency, a construction which leaves much of the responsibility for managing her education with her, whilst also constructing her as liable to fail. The additional work needed is not acknowledged by the HEI but is expected.

The discomfort of the support worker can be read in a number of ways, including their underlying assumptions about the role of support worker, or their individual understanding of what visual impairment is and requires. However, as Hannam-Swain (2018) discusses in relation to working with support workers/personal assistants as a disabled PhD student, the role of the support worker can be complicated by organisational policies and expectations rather than individual bias or assumptions. Hannam-Swain notes that she required personal assistance alongside her non-medical help provided via her DSA. This created a tension in terms of who did what regarding providing support to access amenities or with the practical aspects of her studies. Hannam-Swain's experiences highlight difficulties associated with the support worker relationship. Where there is discord or lack of clarity, as in Maddie's case and as Hannam-Swain describes, there is the potential for this to impact upon student participation.

The role of support workers featured heavily in Emily's interviews. Her account incorporated narratives about a number of support workers and the pattern that it offers is suggestive of inconsistent practices within the institution. It is clear that there were very varied levels of experience and training. In addition, as will become apparent, the use of staff from other services within the university suggests a possible lack of commitment to the support of VI students from those for whom this is meant to be a priority. The emphasis was on ad hoc solutions, not established policies and procedure. This is not to suggest, of course, that those acting as support workers were unhelpful, just that the institutional construction of the visually



impaired student was either that they were so rare that no provision could be planned, or that they were a problem. For example, when Emily enquired whether a volunteer student would be able to act as a guide and support worker around the fresher's fair, the solution was to allocate her a library assistant to assist her to navigate her new environment:

*I had actually 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.*

Whilst the library assistant was a support worker for Emily within that service, this was in a very different context. Here her support was much less appropriate.

Emily's account identifies that interactions with support workers can be contradictory at times, although in different ways to those experienced by Maddie. Whilst she appreciated her library support, Emily was effectively marginalised through the allocation of an older support worker. It meant she could not blend in with the student cohort as she desired. Unintentionally, this served to create a barrier, separating her from her peers by creating a perception that she required a parent, or another older adult, to accompany her. Returning to Titchkosky's (2000) discussion of the 'conspicuousness of blindness', in this context the support worker magnifies the conspicuousness of Emily's own presence as a self-described long cane user at the start of her university experience. As Titchkosky (2000) noted, the stigmatized paraphernalia that signifies blindness, such as a long cane, touching, being guided, emphasises conspicuousness. Emily is faced with a duality of signifiers being 'other' as a disabled person, and as visually impaired, and thus

deviating from the abled population anticipated by institutions, staff and peers. This critical incident meant that from the outset, even at the fresher's fair, Emily was presented to her peers as different and other.

The enforced visibility of impairment that Emily experienced advantages, as Reeve argues, the "observer with privileged information and therefore power about that body" (2002, p.499). Reeve further 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" (ibid), a position she contends adds to the psycho-emotional dimensions of disability. To be perceived as independent was important for Emily in building relationships with her peers. Emily's self-confidence and self-image were, the interview suggests, damaged by the thoughtless allocation of inappropriate support at a sensitive juncture in her university journey. Further, this damaged relations with the support worker:

*In a horrible way, a really bad way, I kind of blamed her for a lot in those first few weeks and it kind of put a barrier between our working relationships. 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, she shows her understanding that her feelings were invalidating of both herself and the support worker and that her anger and frustration about possible social exclusion through that critical incident needed to be focused elsewhere. Reeve (2002, p.496) suggests that the first invalidating emotional response is a frequent one and may have developed as a consequence of the process of internalised oppression which, "relies on disabled people internalising the prejudices and stereotypes held by a non-disabled majority". Emily also acknowledges her fears about how she is perceived by peers, as well as the ways in which she views the position she is placed in by the university. As Reeve (2002, p.495) further notes, the emotional responses that people experience on being

stared at or scrutinised in social situations adds to the feeling of internalised oppression.

The lack of choice about support, something which institutionally compounds the construction of the visually impaired student as dependent and incapable, is apparent here. Emily is afraid about appearing to other students as weak, vulnerable and incapable of participating fully in the activities involved with attending university without help from an older person. Where disability is conflated with dependence and the disabled person is constructed as childlike (Slater, 2012) Emily's account seems to associate her with both, a position which is likely to create obstacles to the development of peer friendships.

Drawing upon previous discussions about the conceptualisation of the ideal student, Emily's experiences here further illuminate existing ableist assertions around who is expected to participate in higher education, and the inherent and covert perceptions which inform the lived experiences of visually impaired students. Given the common-sense approaches derived from a medicalised view of disability that remain present in higher education through implementation and reliance on DSA, alongside cultural notions and expectations about visual impairment, it is perhaps unsurprising that support workers figure significantly in the re-telling of lived experiences. Whilst support workers have been identified as an "indispensable support" for visually impaired students (Bishop and Rhind, 2011, p.186) how these relationships are managed and the impact that a visual representation of difference has upon the relationships and participation that visually impaired students is less explored.

The critical incident with the adult support worker, one she contests others thought was her parent, may also serve to highlight the difficulty of the juxtaposition of being involved in activities considered inherently youthful (Hughes et al, 2005)

with the expectations associated with being visually impaired. Where the ideal student is non-disabled, the construction of ideal youth is also free from impairment and pursues transitions to adulthood. Youth culture is predicated on adult-free arenas (Hughes, 2005), but many disabled young people's participation is dependent on adult support. Whilst university is not a pastime, it is predominantly youthful activity and so what Hughes discusses can be applied here in that Emily and her peers are excluded from inhabiting the inherently youth dominated spaces of university in the same way as non-disabled peers.

In Emily's case, this enforced subject position was further exacerbated by the lack of process regarding her being able to explicitly state the type of support required and the form this would take. She identifies this as being about structures within the university, once she moved beyond seeing it as the fault of the support worker. This shows her awareness of constructions of the VI student (and the broader category of disabled student) in HE and an understanding of the ways in which "the lived experience of disability becomes encoded as a series of signs and symptoms in need of deciphering by normate culture" (Titchkosky, 200, p.218). The accounts of Emily and the other research participants indicate how their experiences of disability are encoded as Titchkosky states. As Overboe (1999, p.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 consistently preserve and protect their unassailably dominant stance. Emily and her peers have little influence on university practices about support worker employment, meaning that the parameters of the problem have been decided by those within a position of comparative power, as have the limitations of any discussion. Overboe (1999) further contends that disabled people may want to trouble the ableist

assumptions in place - such as shown in Emily's lived experience - however, to do so requires that a number of factors are in place, such as clear lines of communication, and/or to present a challenge to the subordinate position enforced upon disabled people. There are many similar situations where disabled people need to consider what they can, do, or *do not* present challenges to the ableist discourses which underpin disabled people's lives.

William, like Emily, felt that his reliance on a support worker created a perceived barrier between he and his peers, noting that rather than develop friendships within his cohort he ended up spending the majority of his time in university with his support worker:

*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...*

William notes that increasingly during the degree his relationship with his support worker, whilst positive and ultimately developing into a friendship, positioned him on the edges of participation with his peers. Whilst William describes himself, and indeed comes across as, friendly and outgoing, his potential to make friends amongst his non-disabled peers on the course became constricted, an experience that he describes as a self-fulfilling prophecy

*"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 may be, in addition, that the presence of a support worker was a visual reminder to his peers of his position as other (Titchkosky, 2009), thus creating a

perceived barrier that hindered interactions between them. William reflects on this experience with frustration:

*I think because I had never had it before [a support worker] 'cos I was an adult when I lost my sight, I was like well this is here to help me but at the same time it would have been nice to have more friends, like the guys on the course, a bit more.*

William had met with the note-taker before the course began and describes the relationship as very strong, due to their similar interests, which contributed to his isolation. It may also be that his lack of familiarity with having a support worker contributed to this, in that he was not wholly aware of how such roles may be perceived and the parameters and expectations associated with this relationship and role.

Nevertheless, as with other participants within this study, the reliance and development of a relationship with his support worker positioned William as 'other' in terms of how his peers perceived him. As Reeve (2002, p.49) notes

[h]aving an impairment that is immediately visible presents the observer with privileged information and therefore power about that body. The gaze is influenced by the stereotypes and prejudices about disabled people, and so the power of the gaze is linked and somewhat nourished by knowledge from within the social domain.

William may be seen here as 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, p.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, p.214) from those who are viewed as the antithesis of the conception of normal. The visual reminder of a

construction of difference conceptualises and re-conceptualises William as different. Whether stereotypical assertions about blindness and visual impairment exist within his cohort is unclear, however, the involvement of his support worker in his university experience is a constant reminder, to others, of difference.

Interestingly, William identifies a different attitude towards him, and a higher level of engagement with him, from a smaller group of peers within his cohort. He identifies these individuals in quite specific ways, saying,

*The ones that would speak to me were the ones that were more outspoken or confident, yeah, maybe the more mature ones!*

It is difficult to speculate why it may be that the students identified as “the more mature ones” tended to interact more with William. However, William’s account suggests that maturity, and indeed confidence, might signify a different understanding of disability and impairment, or simply a comparative lack of fear of difference. William notes that the overarching perception of he and his support worker appears to construct them as one, similar to the ways in which Michalko (1999, pp.8-9) discusses his experiences of the alone-together. In this context, whether the partner is a human support worker, or a guide dog is not relevant. However, the more mature members of his cohort appeared more willing to accept the experience of William and his support worker as both separate and unified entities.

Similarly, to William, Luke and Martin both attended universities as mature students. Their accounts of their relationship with the support that is offered and that which is engaged with differs to that of the younger participants. Luke and Martin, like the others, recognised that the roles of support workers were an important part of the university experience, however they seem more confident in insisting that this role could take a form suitable to their specific needs. Neither

participant took a support worker nor note-taker into sessions but employed them in other ways. What their accounts suggest is that they were very clear about what they wanted as an outcome for their support worker relationships and interactions, and that they had built relationships with peers which enabled them to manage some of the immediate support needs. For example, 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 journal and books is online, so, simple. So, I don't need a support worker.*

Whilst this relationship had come about by accident, this suggests that more formal 'buddying' systems on courses, carefully managed, might enable VI students to integrate more effectively with their peer group and use their support worker's time in a more targeted way. This also ties in with the ways in which Emily identified that a younger student as a 'buddy' for the fresher's fair might have resulted in a less typified construction of disability. As noted above, Luke's clarity regarding what support he required is indicated when he stated that,

*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.*

Luke discusses how he advocates for his own support requirements. Both Luke and Martin are more comfortable with their support requirements in comparison to others who are perhaps still developing the means with which to manage the support relationships. This suggests that in an HE setting, there may need to be some kind of support for younger students regarding advocacy to ensure that they have the confidence to be insistent about their specific needs being fulfilled. It is perhaps indicative that Martin and Luke are the oldest of the participants and that both are male. Both work in professional roles within statutory services and with visually impaired people on a daily basis, all of which may give them more



authority in dealing with support services. Both participants express at various points within their interviews that they are more comfortable in HE due to their age and their existing experiences as a visually impaired person. They also argue that this may not have been the case previously, when they were similarly aged to the other participants, again indicating an intersection between youth and VI that results in a form of double bind. This point is picked up again regarding the ways in which these participants manage the perceptions surrounding their identity as a visually impaired person later. It is difficult to draw out what cultural influences may have been at play within Luke's experiences without his direct reference to how he views himself within society and his exploration of his cultural experiences and understanding. Cultural expectations associated with gender and age may well have influenced the interactions and responses that he and Martin identify. These students note their perceived expert position and influence on their experiences in HE. From there it can be extrapolated that this is based upon their perceived position as autonomous males. Consequently, it can be argued that their gender and professional knowledge status serve to ensure that they are attributed more power.

Interestingly, Hewett et al's (2017) study into the experiences of visually impaired students highlighted expectations from support staff and disability services staff that learners be able to 'self-advocate' for their own requirements. Whilst this initially seems to present practices which appear to be rooted in a strong social model and based on expectations of positive expertise on behalf of the visually impaired student Hewett et al's (2017) conclusions instead showed that there was "a lack of specialist knowledge of how to make accommodations for students with VI" (2017, p.104). Hewett et al's (2017) research is grounded in a bio-ecological model, a position which sits very much in opposition to the stance taken within this

thesis, as ecological approaches draw heavily on normative frames of reference in relation to development.

However, what Hewett et al's (2017) research does show, consistent with the findings here, is that where support and disability services are positioned as expert and accordingly given the power to demarcate what visually impaired students receive, in terms of equipment, time and practical support as a result of the medicalised assessments they undertake, there are significant issues. The rhetoric of self-advocacy could be potentially seen as handing responsibility to the student, but by not taking confidence and experience of it into account, can exacerbate power imbalances rather than correcting them. Again, it is that systems do not deal with individuals as individuals that is a key problem. To be able to use a support worker in ways appropriate to the individual, such as Luke's engagement of his allocated support work time to scan books and access relevant course information, made a huge amount of difference.

The nature of the support worker/student relationship was also discussed by other participants. Georgia notes that the relationship with her support worker was crucial to her ability to participate fully within academic life, yet simultaneously created barriers. Reflecting on her experience of working with a support worker very thoughtfully, particularly in relation to how being perceived as already having a companion, their role as facilitator, and visual impairment, intersect, Georgia states:

*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's a little awkward and it is all a little bit strange and difficult and 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”.*

Despite the associations of deficit and difficulties with managing relationships amongst peer groups, participants in this study showed that they felt their relationships with support workers had been influential on their participation and achievement, even when from the outset these have been poorly accommodated into an overall understanding of the ways in which being visually impaired in higher education can be experienced. Where participants acknowledged the positive rapport that they had developed with various support workers, it is clear that barriers existed as a result of negative connotations associated by others, and sometimes internalised, about having a support worker. This is compounded when the support worker takes over the role of peer, resulting in comparative isolation from a wider network of friendships. There appears a trade-off, then, between being fully included within the peer group and relying on a support worker for particular aspects of study. Negotiating this complex relationship from the beginning appears to require more than placing together a support worker with a student. There appears an issue relating to the management of this relationship between support worker and student, particularly when students experience underlying assumptions about being visually impaired. Perhaps training for both student and support worker is in need of further exploration, guided by the experience of students rather than a top down approach which situates the university or service provider as expert.

### **Attitudes of university services and academic staff**

I now turn to the ways in which this complex relationship with others in positions of power is experienced through interactions with academic staff. This section particularly focuses on the research question: *In what ways is the concept of participation played out in relation in accounts of the experience of visually*

*impaired students in HE?* I begin with a section from Maddie's interviews about university responses to her as a guide dog owner. This focuses on a single critical incident at the beginning of her use of her guide dog in supporting her navigation of the campus. As Maddie recounts,

*The head of the Disability Services sat me down and said oh we have someone in your class with an allergy to dogs, basically if they have the dog around they will have an allergic reaction so unfortunately you cannot go to your lectures this year!*

*Luckily my Guide Dog trainer was with me and she said she would come with me just on the off-chance and I was so glad she did. I didn't have to even open my mouth, she kicked off for me saying it is unacceptable, it is discrimination; she said that the reasonable adjustment is for the dog to go somewhere else whilst I am in lectures.*

*The head of the Disability Service is saying no, the dog cannot go anywhere else, that is against health and safety and asked if she was able to prevent me from bringing the dog onto campus! The GDMO [guide dog mobility officer] was like, no! That is illegal.*

*The trainer then marched off with us in tow and said we are going to go around campus and find a place for the dog to go whilst I am in lectures. We went to reception and the head of the Disability Services was like no! The dog cannot go there because of health and safety and what if someone comes in with an allergy.*

*The GDMI eventually said, "well imagine it was your daughter and a member of staff had said that she cannot go to her lectures?" She said, "you must find a reasonable adjustment and I will be reporting this for investigation." Sure, enough the head came back and said I have changed my mind, maybe the dog can sit with me when you are in lectures. So that is what happened. So frustrating!*

Maddie gives an in-depth example here of the everyday instances which create barriers to participation, and also identifies how useful having additional advocacy can be. The response from the head of the Disability Services is worrying in that it seems that the needs of one student have been positioned as superior to those of another. Severe allergies can, after all, be fatal, but the idea that excluding another student is an appropriate response is concerning. Whilst this seems based in common sense, as the account continues the repeated comment about dog allergies starts to suggest bias and ableism, rather than the needs of another

student, are at the core of the refusal, given Maddie and the GDMO's attempts to find a reasonable adjustment. The idea of excluding Maddie from lectures is, of course, hugely problematic and it is unfortunate that, as the account suggests, it was only a threat of investigation that triggered a solution. Again, this shows the ways in which visual impairment is valued, as "[e]xclusion, intentional or not is a political act, and therefore, a choice" (Michalko, 2002, pp.15-16) and the decision to exclude Maddie appears arbitrary when examined from this perspective. Paradigms within HE regarding VI are shown at the level of access and regarding overall priorities and policies to be in tension with the self-construction of the VI student.

Deal (2003), as noted earlier in the thesis, discusses a hierarchy of impairments, where certain impairments are positioned more positively than others. In this example visual impairment is positioned negatively, which illuminates further the subject position that being visually impaired brings. Examining Maddie's experience through an ableist lens allows examination of the underlying assumptions existent in her discussion with Disability Services. That it is that particular service, one which it might have been thought existed to facilitate the all students' engagement with HE, makes the concept of what is considered an 'appropriate' or 'normal' student starker, as does suggestion of a hierarchy in which Maddie is seen as lower than those with an allergy. Becoming a conspicuous guide dog user, and so pushing the conspicuousness of blindness to the fore (Titchkosky, 2007), may have may have laid bare the underlying assumptions about what is acceptable in terms of Maddie as a VI student existing in a public arena. This unavoidable expression of difference can be seen as triggering an excessive reaction and has caused further tensions in Maddie's experiences as a visually impaired student within higher education.

The excessiveness of the response to Maddie's change of circumstance is notable. This critical incident highlights issues about ableist practices and beliefs which permeate the daily experiences of university. This again raises questions surrounding the underlying assumptions about, and constructions of the visually impaired student and the 'normal' student, and the role of various services and departments which exist within HE in perpetuating, rather than addressing, such assumptions and constructions. I discuss the constructions that participants' discussions are framed within in further detail later.

Emily also discusses how her experiences with academic tutors shaped her experiences within university. She notes that after a certain point she stopped using disability services within her university after problems arose in her interactions with them. Her account also highlights issues between academic staff and services.

*Yeah, the academic tutors where they could be, well the response I normally got was that if I went to them with an issue they would help and try to fix it... in the end like after my 1st year I wouldn't go to disability services for support, I would go to my tutors for help, so they tried to sort it out but then they would come back and say will disability has said this is what we are supposed to do and we have to fill in this form so they would hit a wall.*

*I would speak to my tutor and they would seek advice from disability support and they would hit a wall cos there would be some sort of bureaucracy involved or disability support would give them an answer that didn't really answer the question and we would have to kind of muddle it through on our own and in the end, I think the tutors learned to bypass disability services, 'cos they were just never any help*

Emily's experience, whilst it is not unusual, was frustrating and disappointing for her. Where students are involved with support services the discord between the support plans and how these are put into practice can be significant, with Hewett et al (2017), as noted, finding that where tutors looked towards support services for advice, support staff were often lacking training. Emily shares her experience of this, identifying that where disability services were found lacking the academic staff were

quick to find solutions that often broke down barriers which may have left Emily in a difficult situation. She says that,

*The lecturers were all really helpful. It's really weird for me to talk about uni 'cos I end up feeling like I moan a lot, whereas the only really bad thing about it was disability services and it's hard to kind of put that into perspective cos they were really, really, bad and most other things were fine. Like library assistant, tutors helpful and... like just general people on the campus like cleaning staff in halls, like people were helpful but it's really sad that the people that were meant to support me, didn't.*

Georgia notes how the disability services which she previously identified as helpful and supportive were undergoing significant restructuring. Whilst this did not impact on her experience, her insight into the pressures that support staff were under is helpful:

*I have just met a friend for coffee, she is a notetaker here and she was just telling me that basically, they have cut all the funding for notetakers and library support. I am not entirely sure what is in terms of time, but it has had an impact on the support workers, their wages have dropped considerably as it is not classed as the same thing anymore. It is ridiculous. All the people currently, she is working with, she will get her current rate but when the new people come in she will drop considerably, and she will end up leaving as the money won't be worthwhile, or the way the support workers are treated.*

It is apparent from Georgia's comments that she recognises the importance of an environment that is beneficial to both student and support worker. What she says is indicative of the pressures caused by changes to the DSA. Where this specifically relates to support workers, it is also indicative of the future pressures which may impact upon other services within the university. The increasingly dominant discourse within higher education which promotes a neoliberal and commodified agenda means that priorities of support services are likely to change, ultimately reducing the prevalence of support that is adaptable and focused on groups which require more in-depth and specific support.

Whilst the accounts above talk about tensions around what support was offered and how it might interact with academic tutor support, or focuses on issues

around support workers, Naomi's interviews point out tensions she experienced in relation to both DS teams and academic staff within her studies. When discussing her relationship with her guidance tutor and her lecturers, her anger is articulate:

*No, they were the worst, that was the one that asked me how I could even walk. When I did get friends in the 2nd year, like fell in this really great group of people and it changed my uni experience and it was really good, these lecturers couldn't get their heads around the fact I had friends, instead they were being really patronising!*

*Also, the tutor you have, she's marking my paper! I couldn't exactly complain about her; it was always in the back of my mind like what if she marks my paper down.*

*You didn't have anyone that was impartial, that would have been quite good.*

Naomi experienced a disabling and ableist response from her academic tutors and guidance tutors upon asking them for support to enable her to engage with her course. Tutor comments positioned her as other, revealed a lack of knowledge about visual impairment and also a lack of empathy. Similarly, her experience of the DS within her university was difficult. When discussing her interactions with the DS team members who were positioned to be her named support workers Naomi talks about how the relationship with the DS team, and the academic staff she interacts with, felt:

*You are immediately different in their eyes and that's not what I am like. I understand I need somethings to be a little different and I go about some things in a slightly different way, but everyone just wants to fit in, regardless of disability!*

By saying she felt that she was identified as "immediately different" Naomi notes that a construction of difference seemed to exist from the outset. Naomi later discusses how she felt that this could be overcome by the implementation of specific training and awareness sessions about visual impairment. As I noted in the



introduction, training courses may not make a huge difference, but this does not, of course, negate their usefulness in beginning consciousness-raising. Naomi draws upon her experiences just after her graduation from university and upon her employment within the voluntary sector to reflect on how her experiences could be improved and the cultural limitations which she perceives as associated with being visually impaired:

*I don't expect the world just cos I am blind, I just want to crack on, you know? Like everyone else. It just seemed like they put barriers in place so that I couldn't do it. I would insist they do VIAT (Visual Impairment Awareness Training) training, see what it's like for your student. Sometimes I kind of think what's the point in wasting your breath, let them be like that.*

*I'm not assertive, not in a confrontational way anyway, so I wouldn't do anything differently.*

*I would like to say I would, but I know, in reality, I wouldn't. I know I am a little bit more confident in terms of understanding sight loss now, so maybe I would have said things like you have to do this under the Equalities Act and so on if I had known then what I know now.*

*Since I have been working, you speak to other people who are having the same problems and I can't believe it really, in this day and age, why do things have to be so complicated.*

The responses participants shared regarding their experiences with academic staff show frustration when they are treated as though they are unwelcome or troublesome, alongside the inaccessible course information and resources that are experienced, whilst also highlighting the ways in which academic staff may be supportive in tackling barriers that are in place through the inaccessible systems and procedures. For example, Emily specifically discusses the ways that academic staff also experience constraints when trying to access information and work within existing structures and practices. She talks about the ways in which they provided alternatives to the issues that emerged given the lack of communication with the DS team, such as providing different formats for information:

*like they have to follow some kind of official avenue but then like with me, for my dissertation for example, I went to see my supervisor and asked her about getting the clearance for my dissertation, like it was a massive worry for me, because I had had such trouble getting things in accessible formats in the past.*

*She was like I have loads of books on this topic, am just going to give you them and then you can scan them, that's fine if we do it that way. My supervisor was the head of the module and she was just like kind of, basically, with all due respect, we will just do this this way as it is the most efficient way of doing it and so even they got to the point where they just bypassed disability services.*

Emily's comments show frustration on the lecturer's behalf reflecting Hewett et al's (2017) findings which note a disparity between what it is expected that lecturers and academic staff do and offer in terms of provision for visually impaired students and what is expected from DS staff. Where such expectations are incongruent neither group is able to support the effectively student to ensure needs are met. This leaves the student seeking ways to manage and can add pressure to their already convoluted experience and ultimately lead to additional tensions. In the end, however, given the lack of resolution, Emily's experiences led to her contacting the Dean of Students:

*University services didn't seem to understand and didn't seem to be much empathy there either...I wrote an email to the dean of students and basically told her about those incidents and that I was really unhappy about the supposed support I was receiving, and it wasn't acceptable, and she became a good ally in my 3rd year. She had a meeting with me and said basically she was totally unaware of how I had been treated and what was going on and she could tell it was totally unacceptable, like she wanted me to come to her if I ever had a serious issue again. She seemed very respectful of my experiences and seemed quite keen to take my opinions and perspective on board to improve experiences for students in the future.*

*I had a couple of meetings with her and I know for this year they made a point of getting disabled students, who wanted to, to get them to move into their halls earlier than other freshers, so they could have their orientation and stuff like that, but I know specifically that was something that they did cos I had said that was something I could have benefitted from when I started.*

*So, overall, I think the uni, as an institution has like the best of intentions, but they don't really know how to execute that very well and they just need some guidance, proper training on what to do and what not to do as they seem, especially the disability services, they just seemed like they were just floundering and didn't know what to do!*

Emily echoes Naomi's reflections on her experiences, post completion of university, about the lack of consistency and knowledge around individual student's needs. Emily was able to connect with people that were able to offer support and describes how her experiences were taken on board and engaged with, so allowing her to create changes for future students. She does state that her experience with academic staff was mostly positive and this appears to have benefitted her longer-term involvement in higher education. This may also have changed the experience of all students for the better, as Madriaga et al (2010) found that where tensions exist for disabled students, there are often similar tensions for non-disabled students.

Where Emily notes how her experiences with the Dean of Students brought about significant changes, this aligns with Madriaga et al's (2010, p.657) position whereby providing an inclusive learning environment is more than simply "meeting the requirements of disability discrimination law. It should be about enhancing the student learning experience, cancelling out distinctions, removing ghettoising "barriers" between being disabled and non-disabled". This suggests that such practices would promote a quality experience over an agenda of equality and diversity and thus that "[a]ll students will benefit from a disabled student support, or inclusive practice, agenda" (ibid). Particularly notable is the way in which Madriaga et al (2010) note that staff awareness and understanding require urgent attention, something reflected in the participant's experiences as discussed in this research. Where staff have become involved with research participants this has benefitted the

individual concerned but may also contribute to a more inclusive environment across the university.

Peter's experiences with academic staff varied considerably, in line with other accounts. He requires an alternative format for books and reading materials and this means more time had to be available for him to engage effectively with reading. Where there was a direct impact upon study was not when staff did offer support and advice in relation to tackling the time constraints, but when others were less willing:

*Some of the lecturers were good at saying go ahead and read this but some took a different approach, so we would say to them can you recommend some reading for this particular essay and they wouldn't want to give me core reading that was definitely related to the module as they thought they would give me an advantage.*

*They gave me peripheral reading and we didn't know that until we got it Brailled and then you think now I've got all this Braille, which yes, it is vaguely relevant but it's not going to actually help me to do the essay unless I have the core reading to go with it.*

Peter talked about his disappointment that he was unable to access the wealth of information that was available to him as part of his course, as noted earlier in this thesis. However, his experiences mentioned here limited his opportunity to engage with core, relevant, necessary reading. For these lecturers there appears a conundrum about promoting certain texts over others, and questions over how best to manage the requests which Peter made regarding help to engage with significant texts. Facilitating the development of criticality and engaging with academic skills is a crucial part of the university experience. However, Peter's needs did require a more focused approach given the constraints he experienced regarding the lack of available resources already in a Braille format. A simpler solution and a reasonable adjustment would have been to provide specific guidance to allow Peter the time to have resources produced in an accessible format.

*So, this scuppered me a bit, perhaps without intending to, because they didn't want to show favouritism to me over other students.*

Whilst Peter feels this may not have been an intentional barrier, it ultimately impacted upon his engagement with the core literature and posed a limitation upon him that was not there for other students. This latter point is reiterated in much of the research carried out with disabled students generally and specifically with visually impaired students, for example Hewett et al, (2017); Bishop and Rhind, (2011); Madriaga et al (2010) Fuller, Bradley and Healey, (2004). Accessing course related information is a persistent issue, however, and Peter's account notes unintentional bias related to his disabled status and played out within his interactions with academic staff. Peter suggests that lecturers were concerned with favouritism over other students, or that offering direct guidance was 'cheating', but providing the information that Peter required transcribed into Braille aligns with a reasonable adjustment as is required under the current legislation within the Equality Act (2010).

*I don't think some of them saw it that way, they had got uncomfortable with it, as it almost felt like they were giving me direct guidance through the course*

Where Peter's lecturers felt that they ran the risk of overstepping their role discussions could have taken place to increase their understanding of the practicalities associated with his requirements. In addition, this would have ensured Peter felt more included amongst his peers and classmates. Having discussed the Emily and Peter's experiences, it is important to note that these issues are not specific solely to visual impairment. Hewett et al (2017); Morina Diez, Lopez and Molina (2015); Frank et al (2014) and Madriaga et al (2010) all note that relationships and interactions with academic staff require management and that students have to engage in sometimes intricate negotiations to ensure that they can

fulfil the work required within lectures, to access course related information and to make staff aware of the requirements of disabled students.

Additionally, as mentioned, many of the researchers above note the positive relationships which are shared between academic staff and disabled students, a duality which correlates closely to that which is discussed by the participants within this study. Naomi and Emily's reflections and the various positive interactions with DS and academic staff could be used as a basis to suggest and promote inclusive, informed ways of working with visual impairment and the specific requirements of these students. The accounts also suggest that there need to be broader and more open discussions between students and staff to promote inclusivity. Furthermore, there is a need to ensure that the desire to change and the understanding about why this is necessary is explicit. Without this reflection any developments in HE are likely to replicate current disabling attitudes and practices which limit involvement and ultimately impact upon participation and success.

### **Withdrawing from a course**

Other interviews reveal similar issues to Maddie's with support service provision of adequate adjustments and support to visually impaired students. These are indicative of tensions between HE and visual impairment as constructions and discourses and show how they can have a dramatic impact upon lived experience in combination. For example, Luke signals challenges regarding participation on his chosen degree which eventually led to his withdrawal from the programme and, ultimately, university:

*I actually had an accident the day before starting the course, so I needed two operations to get my hand working again. As you know, if you are severely sight impaired, you use a keyboard to touch type and with only one hand available I only*

*knew half the keyboard, so it was a struggle, but I think that was only part of it. I think the level of inclusion awareness and accessibility on the course was really poor. There were a lot of promises made that weren't kept.*

Luke acknowledges that his accident contributed to issues with accessing his chosen course, through preventing him accessing information familiar ways. However, he also spoke of issues with translating the outcomes of the DSA into practice. Like Maddie, Luke's presence was accepted until, again returning to Titchkosky (2000) the conspicuousness of blindness is apparent. The reality of what the practical presence of impairment means is suggested by the effect of conspicuousness on Luke and Maddie's participation. Thus, it appears in both Maddie and Luke's accounts, that when the outcomes of DSA are put into practice there is a fracture in support services. The lack of dissemination of information, which arguably should provide knowledge about student learning requirements, combined with issues around participation awareness, both within these units and in the wider institution, can create practical barriers to access. As Hewett et al (2017) note where visually impaired students talk about their experiences of accessing higher education there are barriers to participation which pose significant challenges and have and do lead to the withdrawal of students. Participants in various studies about visually impaired students (Hewett et al, 2017; Bishop and Rhind, 2011) state that these barriers can encompass a lack of material in suitable formats, lack of opportunity to make changes to established practices, even reactively, and perceived barriers that preclude feelings of being welcome and able to participate. These may partially, or wholly, limit student access. Issues around communication between institutions and within institutions regarding student needs clearly have an impact upon participation, the individual and the lived experiences of VI students, sometimes to dramatic effect. It is important to note, however that

this may be attributed to the difficulties that arise from working within a system which is rooted within a medicalised dichotomy of deficit related to the person. Those working within these constrictions, may, as a consequence, be dealing with solutions which are not fit for purpose and thus cause a tension in applicability. It is unlikely those working within student support services are not attempting to provide a quality service to those using their services. However as the participants within this study show, the means with which student support is assessed and delivered can be in tension with the procedures required to access it.

As Hughes et al (2005, p.14) note disabled people and particularly young disabled people do not have “sufficient opportunities to ‘go with the flow’. In fact, ‘the flow’ is a source of their immobilisation.” In terms of the ways in which Maddie and Luke were excluded from their chosen programmes, their immobilisation is apparent. Whereas, “non-disabled youth can ‘travel’ with ease through the regimes of value that mark contemporary cultures of consumption and the objects that constitute them” (ibid), in their paths through higher education, disabled people and disabled youth are faced with a tricky route. Where visually impaired students are dependent on the structures and systems that are derived from the “official textbook” of disability (Titchkosky, 2000, p.198) and which pose disability as a problem “presented to people through interactions, with the social and physical environment and through the social production of knowledge.” (ibid), both Luke and Maddie are constrained and controlled by this. As Hughes et al (2005, p.6) ask “what are the barriers for young disabled people, who might wish to develop a project of identity by adopting a particular consumer lifestyle?” For those young people wishing to adopt the identity and lifestyle of a consumer of higher education, mobilisation is required against the notions of disability played out within interactions with, as (Titchkosky, citing Goffman, 2000, p.204) notes, “the others who possess the



potential to stigmatize people... the “normals”... who have many different attributes but who do not, in the interactional situation in question, have an attribute of difference... and do not represent ‘undesired differentness’”.

To engage in HE, then, requires that the individual has the opportunity to challenge what is presented within these textbooks of disability (Titchosky, 2000). Whilst dialogue from the outset between support services and student, were it led by the student, would likely afford an opportunity to develop strategies to challenge disabling barriers, on a more basic level, more understanding of the requirements of individual students and fully translating that into practice would create a generally more inclusive environment benefitting all students.

The accounts reveal a dominant narrative regarding a lack of understanding or action on participation, bar ‘reasonable adjustments’ or the implementation of support services as a tokenistic way of managing student requirements. As Titchkosky (2000, p.207) argues, where,

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.

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 typical sighted pursuits. Higher education, similarly, to other pursuits which require the taking on of an identity and consumer lifestyle (Hughes et al, 2005) presents a challenge for disabled people through the homogenised assumptions which influence participation. As I show

further in the next chapter, these assumptions about the normalcy of sight pervade interactions throughout participants' HE experiences. Where challenges to this are presented by the actions and feelings of participants these are understood through a perception of being on the fringes of participation as a result of the "representation of deviance *par excellence*" (Titchkosky, 2000, pp.2-7) that being blind or visually impaired brings.

In conclusion, this chapter has examined how participants perceive their experiences of participation in HE, and how deficit and limitation are qualities expected of the VI student by the university, showing how constructions of 'the hypothetical blind man' outweigh the actual intellect and ability of these individuals.

With regard to academic staff, there is evidence of limited understandings of specific student needs, which could be addressed via training, but also of positive support of students. This means that where support exists it is most likely linked to individual, rather than institutional, engagement. Where academic staff are particularly non-supportive it seems to be linked to concerns about parity, or simple ableism. Here too, broader understanding needs to be developed. Tensions, as accounts suggest, also seem to exist between departments and services within some institutions.

In relation to other students, this chapter is more about the self-perception of the participants in the research, and their fears and concerns about what others may think, rather than accounts of problematic behaviour on the part of peers, which are discussed elsewhere in this thesis. In effect, the assumptions on the part of services and academics, and their subsequent actions, contribute to the undermining of some the participants' sense of self and confidence in relation to their peers.

Further, the use of support workers, recognised as crucial to the participation of VI students, is something which is seemingly perceived as more related to support

services than students. The service takes precedence over the individual and there is an expectation that what visually impaired students require be delineated by support services. Decisions are typically made without including the student unless they are prepared to challenge and self-advocate, which not all students will feel capable of. This highlights an ableist and normative assumption about what these students are perceived as requiring. Participation, then, is decided in terms of the structural and societal expectations of what it is expected visually impaired people do and what they will be allowed to do. It is also decided in terms of dominant discourses, social constructions and the power relationships.

## **Chapter Six: Identity, being superhuman and transcending the boundaries of expectation.**

I next explore how participants discuss the construction of their identities as students with visual impairment at university. However, this chapter also places that specific construction of the visually impaired self in a wider social context by looking at accounts from William and Emily on the topic of travel to and from university. The comments and accounts included later in the chapter focus on critical incidents taking place in HE or previous education, but the two earlier narratives offer a broader range of material in explaining who the participants feel they are in relation to VI, and who they are perceived to be, again showing their guiding of the research. What their accounts also indicate is how their experiences within HE are, to an extent, simply an extension of experiences beyond it. Consequently, the chapter further unpacks ideas around the research questions; *How does the experience of being visually impaired in HE impact upon the individual?* and; *In what ways is the concept of participation played out in relation in accounts of the experience of visually impaired students in HE?*

The interview material shared here includes elements on the development of self as visually impaired and the ways in which isolated critical incidents as well as wider experiences can impact upon the perception of self. Through this I show how influences on individual and collective identity influence participation within HE and how these ultimately affect the experience of being a visually impaired student. As Peter says, acknowledging his sense of continuity of self, but also his awareness of how VI might impact upon it, *“I already had presumed I was going to go to uni so losing my sight didn’t change that, I was just going to go differently”*. I also further illuminate the ways in which negative assumptions which exist in wider society are replicated within the arena of higher education.

This chapter offers an examination of critical incidents and wider experience that is often excluded from other examinations of life as a disabled student, particularly about socialising with peers. These other interactions are recounted as examples of the inherent disablism that they experience within the higher education arena. This consideration of informal aspects of the student experience, rather than study, situates the research as an innovative contribution to the knowledge base around the experiences of visually impaired students in higher education.

### **Sense of self**

This section examines two small, but nonetheless critical, incidents participants reported regarding being visually impaired and how they have had an impact upon their sense of self, building on previous chapters. These stories and experiences add to understanding as they show the ways ableist responses occur in everyday encounters beyond, but related to, university and the ways in which responses of other people regarding visual impairment potentially contribute to an internalisation of societal constructions as VI. These often manifest within experiential retelling as tension as participants attempt to challenge or think through how they are constructed by others in their everyday lives. The importance of the day to day to the research is that it indicates the wide variety of interactions that disrupt and cause tension.

I begin with a scenario which William shares regarding the retelling of an experience in relation to travel, another aspect of access in relation to HE. Whilst this may seem a simple incident it shows key issues which recur throughout the chapter. William recounts that,

*I was walking onto the bus; I wasn't sure if it was the right bus or not and I always go on and ask the driver. I knew which bus stop I was at, so I knew there was a good chance which bus it was. At first, I thought I was at the back of the bus queue so I asked these people but they didn't really acknowledge*

*me, so I was like ah ok then I shall have to work this out and realised the last of the queue was actually on the bus, so I went to make my way onto the bus and the doors shut on my cane! I was like well this is awkward eh! How has this happened to me. I thought 'well clearly, he didn't see me coming.' I obviously didn't realise he was going to close the doors. I just wanted to get on the bus and go about my day...*

*So, I found my pass, and someone said as I got on the bus 'oh there is a seat available just near you', which I found. This person was shouting at the bus driver as I sat down, really shouting! She is saying to him, 'but he is blind, can you not tell that!' And am thinking well why on earth is she making a fuss about it? Then I realised the bus driver was having a go at me!*

*Later, that same day, the same person who had been sticking up for me on the bus came up to me in a café and introduced herself. I asked her what the bus driver had said, and she said that he was saying what I had done, putting my cane up towards the bus door was illegal. I was stunned. Illegal? He was saying it was illegal and that he could call the police and I am just still stunned!*

*I thanked her for sticking up for me and just wanted to get on with my day, really. It was my cane the doors closed on and I think most people would see that and think oh this bloke is blind like he cannot see the doors closing.*

William's account emphasises his internal monologue and the many small negotiations of the environment that he undertakes take up most of it, itself indicative of the extra effort he must make due to a disabling environment, where, as Michalko, (2002, p.79) suggests within a social model and barriers perspective the environment itself is disabling, "we too stand frozen in the gap between the need to participate within society and the inability to do so... if we are to move in our society we are to do it in the same way that other members do". His experience here is shared by the many disabled people unable to access public transport due to the disabling barriers they offer.

William's interactions, or lack of interaction, with the people in the queue, the bus driver and the passenger position him as different and leave him frozen within the gap, a position similar to that experienced in HE, where not feeling fully belonging is evidenced in the previous chapters. William's position as visually impaired is further driven home to him by the response of the bus driver and his self-construction as a citizen with rights, the person who simply wants to get on with their

day, is noticeably destabilised, as these alternative constructions of him severely disrupt the flow of his account.

Here, the hostility of the driver, directly aggressive, and their unfounded accusation show a distinct ableism, and the construction of William as law breaking is an example of othering. The person who supports William constructs him as a citizen with rights, but also as vulnerable and in need of protection, an ambiguous position in being both positive and potentially patronising. In both cases, these constructions of William, whether as benign, or malign, locate his difference as central to other peoples' understanding of him as is the case with regard to support services in the university context. In addition, William's account begins to draw out processes of intimidation in other people's actions towards him, an underlying factor which appears in all participants experiences. Where the bus driver raises his voice and tries to position William as law breaker he attempts to intimidate William in order to exclude him from participation. William's overall account is indicative of how visually impaired people are portrayed and the limitations imposed upon them in terms of perceptions about what they can and cannot do, the spaces they can and do inhabit and are displayed through the attitudes, actions and beliefs of others. William is thus further frozen within the gap between participation and the inability to do so as a disabled person, and as a visually impaired person, even as one who offers examples of how he challenges this conception of difference in other aspects of his interviews.

William further unpacks and highlights the assumptions that he faces when his visual impairment is brought into the reality of experience saying, "*I think people sometimes think, if they think of visual impairment at all, that it is either completely blind or fully sighted! I think people are confused*". This indicates how inherent expectations about the level of sight expected of, and available to, a visually

impaired person brings about misconceptions and uncertainty around severe sight impairment and sight impairment. Thus, this uncertainty brings “to consciousness the ambiguity that lies between sight and blindness” (Titchkosky, 2003, p.53). Again, this dovetails with his experiences in relation to university, where staff are unsure of how to support him and have a limited awareness that impacts on his study.

This ambiguity about sight is compounded in Britain, as Bolt (2005, p.545) commented, by the fact that the registration system in place is confusing and creates “juxtapositions of a blind person who can read print and a partially sighted person who cannot, a partially sighted person who requires assistance with mobility and a blind person who does not”. William’s experience shows how such confusion is paramount in constructions of visual impairment and how people’s thinking can be informed by what is broadly known or not known about visual impairment through dominant cultural constructions and a lack of accurate information and awareness. Drawing on Bolt further helps exploration of the complex interactions with the bus driver and passengers on the bus. Where language is imbued with limited “terminological typology of the sighted and the blind” (Bolt, p.55) and does not reproduce visual impairment as part of a continuum, instead relying on “simplistic and erroneous” (Bolt, 2005, p.55) constructs of visual impairment, VI remains positioned negatively against dominant and ableist discourses of sight. William’s account suggests how, through these culturally informed discourses of difference, visual impairment and visually impaired people are consistently positioned as other as “irrespective of context, irrespective of appropriation, or even irony, every explicit reference to ‘the blind’ constitutes an implicit reference to ‘the sighted’, a perpetuation of binary logic and its intrinsic division” (Bolt, 2005, p.550).

How William and his peers within this study experience this disabling dichotomy are in line with the interdependence and cultural map related to ‘having



sight' and 'not having sight' discussed by Titchkosky (2003), who also suggests, like Bolt, that these presuppositions employ an overtly dichotomised position of either having sight or being blind, with little existing between, in a binary opposition and thus that this reaffirms the position of those on one side of the binary, those with sight, as in a position of power, in comparison to those, like William who do not. Where William's interactions with the passenger on the bus show this passenger tackling the discriminatory and aggressive behaviour that William experiences, their call to recognise William as having a visual impairment suggests a common sense understanding of those with impairment as needing help, requiring support and as weaker in opposition to those without impairment. Examining William's account in this way chimes with what Titchkosky (2003, p.81) notes, that within these interactions is a presupposition of a world which positions sight as the normative way of being.

William's desire to participate fully, whether travelling or at university, resonates with Michalko's discussion of achieving a self that is rooted within a standard as a normally seeing person. This, Michalko (2002, p.149) contends, when in reflection upon his own previous practices and standards, is "a normal person with all the rights, privileges and obligations that come with it...The privilege was the privilege of normalcy that I could acquire through the interactional achievement of such rights and obligations". William's experience denotes a lack of the privilege which Michalko discusses. By being unable to access the bus or to interact with others in similar ways to those with sight, he has demonstrated, as shown within the responses of others, that in that instance, disability and difference could not "be seen as something that can be included into the existing social structure of society without essentially changing that structure" (Michalko, 2002, p.148). Instead, William's actions positioned him as other, and thus in the expectations and

understandings of others, he did not act within a standard of normalcy (Michalko, 2002, p.149).

Where William expresses his desire to “get on with his day”, by leaving the experience within the confines of the bus he also presents challenge to notions of normativity existent within society and social settings. The action of extending his cane in an effort to hold the doors, a relatively innocuous gesture, has transcended the realms of ‘normal’ expectations about the human body. William’s use of his cane to stop the bus door’s closing on him could be seen as part of the rehabilitative processes that are ‘taught’ to people after changes to their vision, in order to make safe passage. However, as Reeve contends (2002, p.499) “having an impairment that is immediately visible presents the observer with privileged information and therefore power about that body”, so William’s usage of his long cane to ensure his safe access to the bus has provided privileged information and power, just as it does within the university. As Michalko (1999, p.42) notes, noticing and recognising the use of mobility ‘aids’ such as guide dogs or long canes, “put us in mind of blindness and of the meaning blindness has for us”. Consequently, this noticeable aid positioned within the powerful gaze of the observer has situated William in the cultural references which surround visual impairment and this gaze and these privileges are mirrored within other stories shared by the participants regarding HE.

The way in which travel impacts upon a sense of self is also a theme within Emily’s interviews. This was specifically again in relation to public transport, indicating how problematic simply being visible can be. Emily is a regular traveller and she explains that this issue is one which she commonly experiences. There are parallels in trying to negotiate public space in many of the activities of the university, particularly campus navigation and attending lectures. In both cases, these are spaces which offer a point of contact with strangers whose constructions of visual

impairment may be challenging to contend with. Neither of the fellow travellers in her account were known to Emily prior to this interaction. Emily's description is in accord with William's experience, so linking with assumptions about what visually impaired people can and cannot do. Emily said,

*I was on the train today and it was a really long journey and I was wearing headphones and sitting on a table of four, next to a man, with a woman opposite me.*

*The guy came around to ask for tickets and I was going to buy one on the train as it was easier for me than negotiating the machines at the station. He asked where I was going and the guy next to me told him, for me!*

*First of all, I was like, erm, ok, why are you speaking for me? I was thinking if you were a disabled man would you be doing that? It feels like just because I am a disabled woman it feels like you are entitled to talk for me.*

Emily, from the outset of our discussion, was obviously frustrated and annoyed about the ways in which her travel was disrupted by the actions of others. She had sent a clear signal that she did not wish to converse by wearing headphones. As with me and my partners experiences, as described in the introduction, this encounter typifies aspects of the microaggressions and constructions of VI as incompetence or vulnerability involved in everyday interactions. Yet Emily's narrative indicates how she has negotiated a set of barriers to access surrounding the purchasing of tickets from machines, a pre-planned response to inaccessibility where she experiences it. Planning ahead and anticipating potential issues were very much part of her account of university, but, as is the case in this incident, her preferences and decisions were often overridden, removing her autonomy.

Emily notes that her interactions with the people directly around her in the carriage are consistently disruptive and position her within a construction of deficit to the extent of speaking on her behalf. There are parallels here with the assumption of expertise amongst the professionals in the university and their positioning of the

participants as unable to make choices about their own lives. That the other passengers were aware of her destination is worrying in itself, but Emily is more concerned about the overarching position of power that has been assumed and which suggests an ongoing “infantilizing of disabled people” (Slater, 2012, p.205). Slater draws a comparison between the inherently adult responses of ableism and “an ideology of paternalism” which affects responses to disabled people and construct their infantilization (ibid). As noted earlier, this incident is mirrored by that occurring when she was offered a reader which was unwanted as part of the university provision of support. Emily continues,

*Then! I was paying the conductor just after and the woman across from me interrupts and says, ‘Oh your dog is so adorable!’ And I am thinking what! Why can I not just get on with what I need to do!*

Emily highlights that concurrent with the interaction about the train tickets the other person sharing her space interrupts her purchase to talk to Emily about her guide dog. Emily describes a sense of frustration at the ways in which other people react to her and offers a reading of gender and disability in what she says. She pinpoints that constructions of her as a young VI woman mean that these strangers felt a sense of entitlement regarding interacting with her, to the extent of representing her to others. This resonates with William’s discussion previously of intimidation within others’ reactions to his participation. Whilst the intention is perhaps not of malice, that Emily is interrupted constantly is intimidating when it surfaces regularly within interactions with others. As we see throughout these recollections such experiences are commonplace.

Where previously William was frozen in the space between access and inaccessibility (Michalko, 2002) by the barriers to his accessing the bus, Emily has transcended that space with her guide dog. Of course, given the example of Michalko (1999) and Smokie, it is clear that Emily and her guide dog as they sit

together on the train have the same kind of alone-togetherness that symbolises their difference, a point I return to later. All the same, both Emily and William are constrained by the tensions that they experience as they negotiate spaces that are normatively dominated by non-disabled people. These experiences, then, mirror that of accessing university study, in that there is constant tension with others about access. The experience of university is one area in which their accounts could change practice, so establishing a more genuinely inclusive sector. These smaller incidents do not offer the same opportunity to initiate cultural change, although they are very much indicative of the need for it.

Emily describes a sense of frustration at the ways in which other people react to her, and offers a reading of gender and disability in what she says, emphasised when she stated that,

*It is something I am quite conscious of all the time, the way that you are perceived, the way I am perceived, as a young VI woman. Like that interaction on the train, I doubt that man would have talked for me if I was a young VI man sitting next to him.*

This sense of entitlement, in effect power over Emily, is read here as gendered. Various participants noted the intersection of gender, VI, and age. For example, as indicated above, Martin and Luke articulated that being older and male gave them more power in relation to getting what they wanted from university support services. Emily, in contrast, identifies that her gendered experience positions her as comparatively powerless. What she recounts serves to highlight expectations about how a young female visually impaired person is expected to behave. The contrast between these experiences highlights how gender is salient in relation to VI and power. Moreover, Emily is clear that she recognises the ways in which her identity is situated within many different constructions. She draws upon this further as she unpacks the experience on the train:

*There are a lot of different aspects that make up my identity: I am VI; I am a woman; I am young; I am Welsh, you know there is a lot of different aspects presented to him but I know that me being VI, young and a woman, that me being VI is the first thing people notice and the first thing I am judged upon, most of the time.*

In developing her theme, Emily notes that there are several factors which she feels express her identity and goes on to state that these are interlinked, showing an informal recognition of intersectionality. She argues that it is her youth and femininity, both of which can be constructed as linked with discourses around vulnerability, combined with being VI, which are ultimately most problematic. This is because the latter may be seen as compounding the construction of her as vulnerable, and so lead to her being perceived as in deficit by others. That this perception of her is one she sees as negative is indicated by her use of the word 'judged', a term she uses again later in the interview, with all of its connotations about others' perceptions of her worth and value. This too is embedded in her experience of university, where judgement of the assignments that are produced is central, but where judgments about identity and being an ideal student also abound. She adds,

*... at other times, like today, I really wish that me being VI wasn't the only thing and the first thing people noticed about me. It's not the only thing about me, it's not the first thing I want people to notice; it's not the most important thing about me is what I think I am trying to say, and it is really frustrating that it seems to be the only thing people want to talk to you about most of the time.*

Emily's insightful comments about how her identity is constructed and the ways in which it is perceived by others is crucial as it shows how the various intersections of identity can cause tensions within her experiences. Her desire to be recognised differently, and her weariness regarding the way that only one aspect of her identity is focused upon suggests how these identities are culturally inscribed on the body. Where Shildrick (2009) argues that the boundaries of disability are deeply

intersectional and fluid, Emily's discussion of the ways in which depictions of identity are created about her by others, show that what she experiences as fluid and intersectional may be made rigid through the imposition of normative discourses about visual impairment. The various ways in which she experiences being visually impaired or being a woman, or a student, are intersected by the various other constructions at play that are under the control of others. Despite these external factors, however, Emily's perception of her intersecting identities is the process Shildrick (2009, p.25) identifies as "becoming" in the world where "becoming signifies a process that shifts and flows just as the body itself undergoes changes and modifications, not in the sense of wholly foreseeable developments over a life course, but as the irregular and contingent transformations and reversals that unsettle subjectivity – and identity- itself." Emily's sensitive discussion about her identity is significant and relevant to her experience of being a disabled young woman, navigating her lived experience and sharing her experience of becoming within her world.

Emily's reflections on her positionality within the world indicate that she feels she is constantly under scrutiny from others, as in the experience of DSA, exemplifying what Reeve notes, drawing on Foucault's technologies of power which regulate the body, that of gaze and self-surveillance, stating that "the object of the gaze becomes known to the viewer, and the observer gains expertise and control over those being gazed at" (Reeve, 2002, p.498). The panoptic gaze of others that Emily experiences here and as a student, highlights the subjectivity which is present within this gaze. Reeve (2002, p.498), further notes that subjectivity is constructed through "power/knowledge, people are formed as subjects from above by technologies of power... subjectivity is a fluid identity, affected by time and place, culture and society." Where medicalised discourses have cemented disability and

impairment as embodied within the individual, or drawn upon common sense ideals about what disabled people can and cannot do, the places they are expected to reside, the actions and practices that they are expected to carry out, and through such knowledge as that presented by charitable work which is readily exhibited within the public domain, what is known therefore about impairment is imbued with presupposed ideas of worth and value which present disabled lives as those not worth living (Morris, 1991) or from a perspective of ocular-centrism whereby perception is dominated by vision (Bolt, 2005) and subsequently the gaze cast is laden with “stereotypes and prejudices about disabled people, and so the power of the gaze is intimately linked and nourished from within the social domain” (Reeve, 2002, p.499). As a young disabled woman Emily not only experiences the inherent knowledge presupposed about disability, which is played out in the interactions with others, but also about being female and being young.

Emily’s comments about her intersecting identities highlight the ways in which identity for young disabled people “may be beyond the control of the individual and may in fact be re-enforced and even predicated upon forms of social and spatial organisation” (Hughes et al, 2005, p.6). Her frustration at the ways in which these identities are inscribed upon her embodied experience indicate that it can be difficult to break away from these processes and thus draws comparisons with the idea of disabled young people as docile subjects (Hughes et al, 2005), as was played out in her experience of university support services. Emily’s awareness of how disability is understood, whether as a disabled young person at university, or as a traveller, is in tune with Slater (2012) who argues that disabled youth are increasingly subjected to the constraints of a neoliberal agenda of the ideal youth, a process which vilifies young disabled people who step outside the expectations around their participation, whilst inscribing ever more idealist notions of youth as a time which



“promises not just beauty, but also health and the good life” (Slater, 2012, p.206). Where the ideal body and mind is youthful, those bodies and minds that do not represent and match up to this ideal are positioned as “deficient, deviant and disposable” (Slater, 2012, p.206). Where Emily discusses the various constructions that she believes form her intersecting identities she is troubling the dominant discourse of disability, passivity as a disabled person, and the abstract conception of youth as ideal. By doing so she presents a challenge to the hegemonic construction of disability which is taken as the common-sense view that surrounds disability. Slater ironically cautions that “we do not, therefore, want our young people to be too active” (Slater, 2012, p.724) as by doing so presents a challenge to the inherent idealism that a conception of youthfulness is rooted within and as such opens up discourses about the body. Here is a reminder that “one is compelled to conclude that youth and disability constitute two very distinct and incompatible tribes, identities that clash and recoil from one another” (Hughes et al, 2005, p.13) as examination of Emily’s identification of her intersecting identities uncovers underlying oppressive beliefs about disability and impairment held within the social and spatial organisation and construction of society.

Emily notes a juxtaposition between expectations about her and about what she can and cannot do. She attaches this to cultural constructions of what it means to be disabled and the stereotypes and dominant discourses around it. She argued that,

*...there is the bigger problem that it only seems possible to categorise disabled people into either superhumans, or subhumans, so we are either amazing, or completely helpless and there is no middle ground and you end up having to go above and beyond!*

Drawing on Crow’s examination of the polarisation of disabled people through the imagery and depictions that occurred within the 2012 Paralympics, Emily’s

examples of superhumans and subhumans resonate with Crow's analysis of the juxtaposition of portrayals of disabled people as either scroungers or superhumans, whereby "immersed within the name-calling of superhuman/fraudster/scrounger/victim lies an unease of greater magnitude, a deeper message of the social value placed upon disabled people and the function that disability can serve within a society" (Crow, 2014, p.175). Emily's constructions are similarly located in a binary opposition, one she argues is excessive. This shows her understanding of the ways in which disabled identities are understood as exceptional, but only through being either much better, or much worse (or worth less), than anyone else's. This binary opposition within disability is one of which she is very conscious. As she says,

*You cannot be average when you are disabled, you have to be exceptional to get noticed or you know, you are just automatically judged as being nothing and then you are completely underestimated.*

Emily is clear on how these constructions about what it is to be visually impaired inform the expectations of others in all aspects of her life, including study. Whether that construction involves delivering congratulations or reinforcing the stereotypical construction of disabled people as inferior or weak is in many ways not the point. Instead, Emily's insightful, yet clearly frustrated, comments show how, "The qualities associated with disability and impairment symbolise negative value and deficit with respect to physical, cultural and social capital" Hughes et al (2005, p.12). The construction further illuminates how disabled people are only allowed to inhabit and achieve within spaces created by non-disabled people and within the expectations non-disabled people hold about disability and impairment. Ableist perspectives such as this position the normative, non-disabled ideal as the ultimate achievement and reinforce disabled people as inferior.

Finally, returning to the physical presence of her guide dog, this aspect of her travelling experience means that Emily is perceived first and foremost as VI, as

she is in university This too, she argues, is seen as an indicator about her visual impairment and so her capacity and ability:

*It is just the way that the world works, and I cannot really hide it with the guide dog. I was thinking in some ways I quite like the fact that I am obviously VI, in some ways, with the dog. It immediately gets rid of the elephant in the room, because you can't ignore it, you can't hide it, the dog is there, and it is very obvious what she does.*

Emily suggests that her identity as a visually impaired person and guide dog owner implies a symbolic visual representation of her impairment. In turn, this symbol of obvious visual impairment brings with it assumptions about Emily, present before she is able to make herself known. As Michalko states, "Dogs as guides *symbolize* a version of blindness" (1999, p.39). The collective understandings associated with the presence of a guide dog, inform the ways in which Emily is constructed within the specific situation described above, but also more widely. Furthermore, where Emily suggests that she 'quite likes' the visual cue that her guide dog's presence brings, she perhaps highlights relief that this presence brings about respite from intrusive questions and comments that are often part of the experience of being visually impaired. However, as Crow (2014, p.177) contends

Simply to be visible in public spaces is not enough, for to change dominant notions of disability is not a passive process. Rather, the more we become actively visible, creating selves which counter, contest and engage as we move through public spaces, the more we demonstrate a decoding of images in its most profound and active sense. In a time of increasingly hostility, to be publicly visible carries risk; however, to counter the images, it has become more crucial than ever. In making ourselves visible, we proclaim flesh-and-blood images that embrace the complexity and multi-layered identities of disabled people.

To be visible, to challenge the imagery that is associated with disability requires a distinct confrontation of the dominant discourses. When Emily shares her feelings about the conspicuousness of her guide dog and the associated imagery she perceives constrained within this, rather than suggesting passivity, it can be read through a lens of resilience. Emily's desire to withdraw from the constant influx of

questions and assumptions which present themselves to her can be a form of challenge to beliefs held about disabled people as passive. In effect, in refusing to respond she turns the gaze of others back on themselves as “[b]lindness reflects sight and it shows sight to itself, something it cannot see without blindness” (Michalko, 2010, p.5) and as such where sight is shown to itself “it is the time for sight, for normalcy, to develop self-understanding (*ibid*). Within this the gaze is reflected back “by disabled people, from impaired bodies to the social body, which, hitherto a model of innocence, is now identified as the source of the disorder” (Hughes, 1999, p.159). Deflecting this gaze back onto society shows how the inherent prejudices and oppressive understandings about disability and impairment influence how disabled people are valued (or not) and how society creates and recreates disability both within a historical and contemporary framework.

Emily’s quiet and firm refusal to engage resonates firmly with Michalko’s (2010, p.5) suggestion that “the subjectivity of blindness, blind people, making an appearance in the world as figures who figure out is the time for sight to figure out that it configures not only a ‘just there’ world, but also a sighted subjectivity, sighted people”. The construction of this sighted subjectivity and sighted people is one which has to position blindness in opposition to the normalcy of being sighted and experiencing those things that can only be appreciated by seeing, rather than conceiving. To present such a challenge is difficult, but Emily and her peers do so both in and outside of university, in HE particularly refuting constructions of blindness as ignorance, as they negotiate a world which normatively values sight and pushes blindness to the fringes of participation. As Liz Crow (2014, p.177) suggests “not only do we need to become our own producers, but our own distributors too”.

## Peer reactions to blindness

I turn next to two critical and discriminatory incidents shared by Peter in a rather different context, that of socialising in a local club with student peers. Although he talked about these incidents in interview at the same time, reinforcing his key points about power and disability, the two took place several years apart and in different clubs. In the first, shorter example, Peter talks about how he was using his long cane as a mobility aid at the club when it went missing.

*I can't guarantee who it was, but my cane went missing. I always put it on the table in front of me, so I can locate it easily, however this time it vanished!*

*I had to eventually get the lights put on, so I could get help to find it, I literally was trapped in my seat, couldn't move.*

*I mean this was a bunch of students I didn't really get on with, they were my housemates, but they were always doing silly tricks like that.*

For Peter, this incident highlights his forced dependency on others to participate socially as part of HE, and the removal of his mobility aid reinforces his subject position as vulnerable and dependent, or as capable of being expelled. Peter depicts this in terms of being tricked, noting that this was something he experienced on a regular basis and a constant part of his relationship with his flatmates, as mentioned earlier regarding his experiences in university accommodation. That he describes himself as being trapped has both literal and emotional overtones given the issues he outlines that he had with this group.

Peter also recounted a separate incident where he was forcibly made to inhabit a particular space. This reinforces the previous example in focusing on issues of power and gender, and reflects what Emily says, although in different ways from her account given that in her narrative femininity is the focus. Here, masculinity and power are significant, showing how disability intersects with and is seen as antithetical to 'norms' of masculinity by some men to the extent that they mock and

physically threaten those seen as different. Peter described the incident by saying that,

*It happened to me and my friend, we were out with another group of friends and there was this lad who was out, was friends with some of the group but I wouldn't count him as a friend.*

*Basically, he was very over confident, goes to the gym, physically strong and to show off in the club he thought it would be hilarious to pick me and my friend up at random without us knowing or wanting it to happen.*

*He thought it was hilarious. He only picked on us two and because we couldn't see him coming to do it and every now and then without warning we would find ourselves lifted in the air and paraded around as if we were some sort of trophy.*

*No matter what we said or what we tried to do to stop it there was nothing we could do. I am pretty sure, like I said, if we could have seen him then at least he wouldn't have got away with it, cos we could have tried to avoid him but instead we spent our whole night not knowing what was going to happen next.*

Peter, and his friend are subjected here to what Goodley and Runswick-Cole (2011, p.602) describe as “the violence of disablism”, whereby their experiences are bounded within “responses that are perfectly compatible with a culture of disablism that pathologises difference, individualises impairment and maintains ableism” (Goodley and Runswick-Cole, 2011, p.609). Goodley and Runswick-Cole’s discussion of the violence of disablism, whilst focusing on predominantly on the experiences of disabled children and their families, also illuminates how values are, sometimes unconsciously, fetishized onto disabled bodies, such as “vulnerable, dependent, broken, tragic, exotic, uber-different, pathological, violent” (Goodley and Runswick-Cole, 2011, p.609). Where these values are projected onto the disabled body, in this case Peter and his friend, the results, discussed by Goodley and Runswick-Cole (2011) are a disavowal of disabled people and the value associated with being disabled. It is difficult in the encounters described by Peter to understand the ways in which people react towards disability. Such abusive acts, for this can be read as threatening rather than playful, are intended as a forcible reminder of power

and strength on the part of able-bodied student peers. Further, in this case, the action was very specifically designed to ensure that visual impairment was reinforced as a weakness. Whilst there is much legislation which is posited as a method to challenge and tackle discrimination there is little means with which to tackle inherent prejudicial attitudes that stem from the social identity attached to being visually impaired and which is rooted in maintaining “the ideal of the inherently stable non-disabled body or mind” (Thomson, 2002, p.5). As Peter discusses his experiences within the social environments it is apparent that rooted within them are discriminatory behaviours towards disability. In particular they reveal intimidation as a tool, as an explicit act. Here it is used to challenge Peter’s existence as a visually impaired person.

Acts like this show how disabled people are forced both literally and figuratively to only inhabit the spaces that are deemed as suitable a spatial policing of disability. The actions of these individuals, then, was designed to send a signal about the club as an unsuitable location for Peter and about the expectations that were placed upon Peter and his friend as a result of the construction of disability held by those around him. Peter goes on to talk about how he tried to get some control in this situation, but also indicates that this was ultimately futile. In part this was because of the nature of the space, in being loud and busy, but also because his remonstrations and anger served to further encourage this abuser.

*I was very angry!*

*I kept trying to shout at him, but you are in a club and that is it. You don’t know when it is going to happen until you are being lifted up. Then when you are lifted up there is nothing you can do about it except sort of try and struggle and probably look ridiculous in the process...*

*It was a night out; I guess he was just ‘letting off steam’. Maybe asserting his male alpha-ness. It is idiocy though; he was just being a prick.*

*It was astounding and humiliating.*

*I don't actually think I could stop it though, that's the thing there was nothing I could physically do, he was physically stronger than me, he could see, I couldn't hear anything 'cos I was in a club, there was nothing. I was totally defenceless.*

Peter reflects on the actions the possible motivations of the individual who put him in this vulnerable position and abused their able-ness to belittle and dominate him and his friend. He unpicks the experience in aiming to understand the power differential, summarising that he was in the end 'defenceless' and unable to challenge the actions of this individual.

When Peter describes himself as looking 'ridiculous' and feeling humiliated he is thinking about how he looks to his university peers, despite the fact that they are responsible for what has happened. This is suggestive of his position at university as on the fringes of participation. The 'tricks' he experiences are not only about his being in the club, but also about his participation in HE. In neoliberal ableism those who are unable or unwilling to participate in what are considered valuable and worthy activities, such as work, consumerism and education are increasingly pushed to the fringes of participation and consequently deemed as deviant or deficient or identified as "scrounger, waster, dependent" (Goodley, 2014, p.100). Whilst Peter does wish to participate, experiences like these two incidents serve to expel him from spaces considered valuable, in this case spaces attached to consumption, the club and the university, policing and maintaining them as exclusively for non-disabled peers through exploiting what Peter thinks of as his vulnerability. They feel empowered to do this, in part, because disabled people are routinely positioned as vulnerable or weak. Deal's (2007) examination of aversive disablism suggests that ingrained and arguably well-meaning thoughts around disability position disabled people as in need of care and support without which they are unable to exist.



Furthermore, when Peter talks about the latter experience at the hands of the group member he illuminates how that individual's position of superiority brings with it expected characteristics such as strength, health and power. To be well, to be strong, to be healthy are all idealist constructions and polarise disability as the antithesis of this ideal. Peter's impairment is marked upon his body and this positions him clearly in the realm of 'other' and accordingly brings with it negative responses. Peter uses this critical incident to reflect upon his perceptions about the beliefs present within wider society about visual impairment and disability, stating that:

*I don't think someone is walking around having prejudicial thoughts constantly, it's something that happens in the moment because it is driven by a stereotype, predetermined, something they are not necessarily aware of.*

*When you start challenging these behaviours and thought processes in your own head is where you realise where they are coming from. Most people don't have time to question the situation and not many people have the situation to question their own beliefs.*

Here Peter unpicks the creation and playing out of subconscious prejudices and beliefs by others. His reflection on the ways and means in which people hold and act upon stereotypical constructions is used in his account to modify, re-create and reflect on his identity as a visually impaired person.

He continues by discussing the way in which he feels about his identity as a visually impaired person and the tensions that he feels aware of in everyday life surrounding that identity.

*There are times I worry I am "too" visually impaired and live too much like a stereotypical visually impaired person.*

*My whole, entire, lifestyle is surrounded by and centred upon my visual impairment. There are worries that I have stereotyped myself at times! I don't watch television, because I got out of the habit, now I am more interested in the radio, you get hooked in so next time it is on I will want to listen to it again whereas I haven't got that with the telly, I don't want to catch the next episode. Do you see what I am saying?*

*I don't know, I do things that I can do as a visually impaired person, that are accessible to me. I have a lot of visually impaired friends, my job is around sight loss, and my knowledge is around sight loss. I feel like I have cornered myself in sometimes and I do worry that that does impact upon my ability to make non-visually impaired friends, but other times I don't care, it really depends on how I am feeling about the world at the time!*

Peter identifies of his own pre-conceptions about visual impairment, stating that he might adhere to and perform a stereotype, but his account also suggests how embedded he is within his community. He recognises his identity and his feelings about it as fluctuating. Peter then discusses potential friendships outside of the VI community, stating that they inevitably starting from assumptions, values and beliefs about visual impairment which are projected onto him and have to be overcome:

*I do think I've probably got more levels than I sometimes assume... when you do meet new people most people you still have to over that initial you are a blind person bit, you've still got them to be more accepting and normalise it for them first before you have the potential to become friends.*

*The first bit is invariably about the sight loss bit then you have them going away still thinking of you being different or inferior or special or whatever term they come up with and you know, you aren't on an equal footing with that person until they understand it where you can just be you.*

Peter describes here how he feels interactions with people develop, in an account that has similarities with Emily's, where only one facet of identity dominates encounters. Taking on board pre-conceptions is needed first to sound out what he feels their expectations are of who a visually impaired person is and what they can do, before moving beyond that. This is not depicted as a straightforward or simple process. Peter's accounts of visual impairment both in university and outside of higher education suggest that he is faced with a constant negotiation and re-negotiation of his identity in the light of the preconception's others hold and present. Peter's comments, in which he enters into a negotiation with strangers to develop an identity within the preconceived boundaries associated with being visually impaired before hopefully moving beyond that, draws out how VI identity generally

is conceived, presented and changed by the actions and beliefs of not only the visually impaired person, but imposed by societal and individual actions, reactions and responses.

Similarly, to Peter, William also discusses the negotiations which take place around the creation of a visually impaired identity and the preconceptions about visual impairment which contextualise these interactions. In this particular interview William talks about how he experiences the construction and discussion of a visually impaired identity, as a student in higher education student, as a first step to building relationships, much as Peter does:

*I think in some ways it can be a conversation starter, like seeing me using my laptop, initially it might be them going what on earth was that as the voice over is going at like a million miles an hour, how the hell do you understand that!*

*I start talking to them about it and them asking questions like that might conjure more questions like "oh, how do you do this, or that" and I am the sort of guy who never minds talking about it. Like, if people have questions, are generally interested, and have the right intentions I don't mind answering questions about my visual impairment. From that it flows into the conversations about the fun stuff that you actually want to talk to people about, "where are you from" or, "tell me a story" or music and films and sport!*

William notes here how it takes a while to get to the point of talking about things other than his identity and conception as a visually impaired person. As with Peter, he has to navigate through the fascination of non-VI individuals about visual impairment. Without doing so he is unable to have further conversations and interactions. He further reflects on this by stating that:

*I think it isn't malicious, it is in the self and I guess you could call it some sort of subconscious discrimination where the only thing they want to talk to you about is your visual impairment and they fear it a little bit.*

Here William indicates how subconscious expectations of visual impairment are at the forefront of the interactions he experiences. He also notes a well-documented

fear about visual impairment and disability. Preconceived ideas and beliefs about visual impairment often are based within a dichotomy of fear and fascination. William addresses this directly, identifying the ways in which he accepts as a natural part of the experience of being visually impaired, the fear others hold about being visually impaired and his self-perceived responsibility to break down negative assumptions. He continues on the themes, saying,

*Like in the context we have been talking about, socialising, if you can ride that initially and just talk to people then they start knowing who you are and ask questions about you and who you are then that's the position that you want to get to!*

*You can get to that position quite quickly and you know that person is a good person, and like even better, for me, if they start to be able to make a joke about visual impairment.*

*Or, even better, start laughing at your jokes! I make jokes about it all the time and then it's the deep intake of breath and oh that's awkward feeling from them and I am like no, it's not, laugh!*

William notes here some of the ways in which bringing the subject of his visual impairment into the conversation breaks down some of the barriers that surround the ways in which he interacts with people. The subject of visual impairment becomes a shared topic and one he uses to deflect negativity and awkwardness. However, William is perhaps identifying that within his interactions, similarly to that which Emily discusses earlier, the first thing that informs interactions is visual impairment and difference. Assuming that the knowledge that is mostly 'out there' about visual impairment is rooted to some lesser, or more likely greater degree, in the common-sense, individualised understanding of disability as "a biological deviation from the 'normal body'" (Michalko, 2002, p.30) then the underpinning notions of the initial interactions William discusses here are identifiable. As Michalko, (2002, p.31) notes, "[t]here is a hegemonic finality that comes with the biomedical model of disability. It advocates the primacy of the natural body for the human condition and promotes disability as an unnatural biological condition". This

concept which is evident within William's broad recounting of interactions where he suggests that the questions about visual impairment are an inevitable part of his dialogue with others and that to move forward requires this discussion.

What the comments William makes suggest that what is happening in these interactions is that William is acting within the realms of the expectations that are held about visual impairment. In doing so William confirms that he is aware of the boundaries to his participation and autonomy and of the common-sense ideas around disability likely to inform expectations unintentionally. Regardless of intention, William is expected to confirm, to the person he is talking with, to the beliefs held about visual impairment and thus the values and expectations that are placed upon a visually impaired person. In effect, he is further cementing the "hegemonic finality" Michalko (ibid) speaks of.

William and Peter's reflections upon VI identity and socialising with student peers address what kind of dialogues they can have with them. They have developed ways to address their visual impairment that promote their autonomy within interactions and persist in entering spaces that they feel should be accessible to them. By doing so both offer up a challenge to the dominant ableist attitudes which pervade interactions. Both their narratives highlight, however, the ways in which they are constrained within the temporal space that non-visually impaired people construct, as their challenges are mired within the expectation's others hold about visual impairment. One aspect of this is noted by both participants when they focus on discussing how in order to inhabit their social spheres at university and associated spaces, they play out a role of being stoical, accepting and deferential in order to be accepted by others.

Stereotypes and pre-conceptions also appear in Maddie's accounts, where the response of others to her impairment highlights the underlying beliefs people

hold about the stereotypical disabled person and this brings about a return to specific structures within HE, in that the focus is on her interactions with the disability support services team within her university. For example, Maddie retells her experience of working with a team member to develop her allocation of support:

*The staff member said, “well this isn’t a special school, it is mainstream, and we have another thousand students to support, and we think you have been quite spoiled in the past with the support you have had.*

*Apparently, it was meant to be a joke!*

That this is a disability services team member, someone specifically employed to work on breaking down barriers and supporting participation, it might have been expected that they would have more understanding and sensitivity. However, as Goodley (2011, p.142) suggests, whilst more disabled students are attending post compulsory education “questions still remain about the extent to which they belong”. Such questions are perhaps formed on the back of underlying assumptions and assertions by those within the educational arena about the value of participation and about the value of disabled people more generally. This is in tension with achieving participation, which is also problematic when education is “in a constant state of flux as priorities change and cultural influences come to bear” (Mallett and Runswick-Cole, 2014, p.11) and as such participation becomes “a process and never an end point” (ibid).

Michalko (2002, p.133) notes that “[p]articular images of disability flow from the modern idea of the expert, from which flows images of disability steeped in an ideologically based version of knowledge about disability” and as such these expert ideas, within the experience of special educational practices “insist on such ideological practices as acceptance and adjustment as rational responses to disability”. Thus, rational responses to the practices of participation conflate disability with the need to make changes to accommodate difference and thus

“disabled people are in danger of being with a politically correct backlash – where ‘inclusion’ is seen as devaluing and ignoring the educational requirements of ‘normal’ (read unproblematic) children” (Goodley, 2011, pp.147-148) and of course, adults.

In relation to Maddie’s experience, the response from the staff member working within the disability services team shows how “[n]eo-liberal conceptions of education and the neoliberal child find their way into the subjectivities of children, parents and professionals” (Goodley, 2011, p.146) thus likely informing the actions of this professional. For Maddie, these neoliberal constructions that inform higher education, and which influence the ways in which she is constructed within it promote a subject position whereby she is constructed negatively regarding the support allocated through her medical DSA assessment. As discussed previously where medicalised notions of disability position impairment as within the individual this creates a subject position of the disabled person as deficient, in need of help and care to overcome their impairment.

Maddie’s positioning by the staff member as “spoiled” suggests that she is expecting too much, more than has been delineated, more than she deserves. The staff member links this with Maddie having experienced education as a disabled child. Furthermore, the comment suggests a childlike state, a position of vulnerability and also potentially suggesting a capacity for disruption. The word spoiled, of course, can also refer to moral corruption or physical damage, linking in other ways with dominant constructions of disability. The staff member can be seen as conflating all of these potential meanings and positioning Maddie as disruptive to the normative, ablest way of things.

## Scrutiny

This idea of the disabled young person as an overindulged child links to ideas within neoliberal philosophy about disabled people as scroungers whereby they are positioned not as needing support, but as using up resources that could be applied elsewhere or wanting something for nothing. Following on from the example above, which shows this idea playing out in a professional context, a similar construction is revealed in her account of a social context with peers, suggesting the dominance of this cultural construction. Here Maddie discusses a night out, early on in her university experience:

*One night I went out, trying to fit in and I had a bit of fresher's flu, so wanted to go home early. So, I said I am going to get a taxi, would you mind taking me to where the taxi is when it comes, and they were saying "oh my god she is so rich she can afford taxis." It was a shame that they completely didn't get that it was a necessity for me, 'cos you know, my DSA, etc.*

Lack of awareness about impairment and preconceived prejudicial and discriminatory attitudes affected Maddie's experiences with her peers. Whilst Maddie might have been able to discuss this, as Peter did, to overcome stereotypes, sharing with a number of housemates whose views served to reinforce group prejudice made this a difficult task. This affected the ways in which Maddie developed relationships with her peers and housemates. As Maddie said,

*I had delivery of my equipment, the delivery men were carrying the boxes up for me and they were all like oh my god she is made of money and saying things like "oh if you want a drink just ask Maddie, she is made of money, she can buy taxi's look at the stuff she got the other day". I didn't want to say to them well actually I didn't pay for all this as it is DSA, that is different, but you don't want them to presume you are getting benefits, I don't know it's really awkward.*

Maddie expresses a duality associated with the ways in which she believes receiving equipment would position her as different. This is linked to a wider social misconception in which what is a necessity for living for a VI individual is seen by



non-VI individuals as luxury, wealth, or if identified as coming from the state as welfare benefits, as undeserved. Both are tricky positions for her to negotiate in an already intricate landscape.

Maddie's narrative highlights how, in order to participate in the ways that others do within their university experience, she has to find alternative ways of doing things. However, that disabled people are vilified as scroungers is very clear in the comments her peers make. As is shown repeatedly within this research idealist notions of normativity seek to position difference as deviance and as such "dis/ability categorisation is process of disavowal: it provides and steals" (Goodley, 2014, p.167). To access resources, or equipment or to participate similarly to non-disabled people often necessitates a categorisation with "disability diagnosis giving access to support systems and welfare systems" (Goodley, 2014, p.167) and this is replicated within the arena of higher education, where in order to access activities, resources, materials, situations both educational and social there is a requirement to take on a disabled identity. When Maddie outlines her flatmates responses to her and her fears about how they would perceive her if they knew she was entitled to benefits and how problematic it would be to explain, Maddie is potentially replicating the discourses that are often positioned within societal responses to disability.

This idea of scrutiny by others was also apparent in Peter's account, although tied not to notions of material wealth, but to his physical appearance and the way it combined with visual impairment to construct him as vulnerable, weakening his subject position. Here youth is a factor, as Emily mentioned regarding travel. Constructions of youth as dangerous seem not to apply when being VI is involved as visual impairment is typically positioned as the embodiment of vulnerability and imperfection. As Peter says,

*I am under scrutiny perhaps, people make assumptions. The problem that I have is that I have a number of things going on. I look young, I get mothered! ... I got led by the hand, across the road, the other day. That was interesting and bizarre! I had stopped, and I always put my hand out slightly to check around me, and someone just grabbed it and pulled me across the road! I don't know, they must have just thought that I wanted to cross the road, put my hand out just in case someone was there, and they would just take it, and someone did! I think it is just people's default setting, to take over.*

Although Peter has been a guide dog user for a number of years and travels independently across his local region his appearance and disability are assumed to make him dependent. This shows an intersectional understanding of identity. Peter shows here the ways in which other people position him as in need of support or care, reiterating the ways in which disabled people are often positioned as childlike or vulnerable. He shows his understanding of how he is constructed when he reflects upon incidents such as this, saying,

*Well, I think it is a normalisation thing, people perhaps very rarely encounter someone with a disability perhaps. Therefore, that person's disability is the thing they see.*

This comment also relates back to those made by Emily, Peter and William, about the centrality of VI in how they are understood by others, something which has an impact upon their sense of self, and their interactions and relationships with university peers.

### **Developing identity as an independent visually impaired student in HE**

In the following interview extract, Naomi discusses how when attending university, she wanted to keep a level of independence and autonomy without being too far away from her family:

*I had been away at school so when I went to university, I had been away so long that I really didn't want to go back home, I didn't want to be too far away from home either. I ended up an hour away from home, so my mum is not*

*going to come and try to make me a brew in the mornings but then also if I did want to come home then it isn't too far away either.*

Naomi is clear that she wants to retain the independence she feels she gained whilst attending a school for visually impaired students. However, she is clear that at times the support of her family is valuable in terms of challenging disabling barriers and practices. Emily similarly notes that as she went off to university, like Naomi, she was keen to keep the independence that she had gained by boarding at a school for visually impaired young people, stating that,

*I wanted to stay not being on my parent's doorstep, but I wanted to not be too far away either.*

Both had been involved in specialist, segregated education. Mallet and Runswick-Cole state that “traditionally, debates in the global North about inclusive education have focused on where a child is educated – in “mainstream” provision with non-disabled peers or in “special provision with disabled peers” (2014, p.111). Rather than examine how this may, or may not, improve participation in university more generally for disabled young people, I align myself with Madriaga’s (2007) assertion that education reflects the wider societal attitudes and inequalities faced by disabled people. When there are very specific expectations dominant within society around how visually impaired people are expected to act, behave, accept and participate there is a tricky juxtaposition of independence and dependence at play. In both cases the participants had expectations of university that had emerged from their experience of school, assuming that there would be distinct similarities. What both later describe however, is that independence in HE was accompanied by isolation.

Where Naomi discusses the desire to have her parents close, yet far enough away to allow her independence and to experience higher education, this duality is not unusual in terms of young people attending university. Experiencing higher

education as a young person away from home is a rite of passage. However, the rite of passage is often different for young disabled people given the construction of disability as dependence. For example, Maddie's comments below highlight how there appears to be a perception that there should be a stronger reliance on the family in terms of VI students, again a stereotype. Maddie says,

*I have had some pretty sad experiences of people thinking I am not capable. I got in a taxi and someone said oh have you always been blind? The usual things they ask and then they said, "and where are your parents?" I was like well they're at home, 'cos I don't live there anymore. They were like "that is disgusting!" I was like sorry? They said, "you are their daughter and they brought you up and they aren't even going to look after you."*

*I had moved away to university, I chose to move out! I was really sad about that, you know? I was trying to say but I chose to move out and they were still arguing with me! They don't see it that way, you know, disabled person, can't do anything, parents should be doing it all for them!*

This assumption about dependence is a stereotype reflecting underlying beliefs held about disability and impairment that are further influenced by the perception of the experience of disability throughout the life course. Where disability is held as tragic, expectations position disabled young people as within a cyclic dependency (Hughes, 2005; Slater, 2012). When disability is within the realm of processes that exhort cure, rehabilitation and care, such as in charities, educational practices and common-sense views, to be independent and to challenge these conceptions disrupts inherent attitudes about disabled people. Maddie's experiences here show that assumptions about dependency and VI are both ongoing and so powerful that her independence results in the demonising of her parents.

The way in which these constructions regarding dependency and disability combine may result in isolation for the visually impaired individual, rather than integration amongst their peers, something which has implications for the experience of university and student identity. Addressing an earlier educational

experience, Emily describes how being the only visually impaired person in her small community led to feeling isolated amongst her peers and to an extent within her family. She states that as a young person she had no real sense of community until she attended a residential holiday for young visually impaired people:

*I think being part of a group wasn't something that I had ever been part of before. I was the only visually impaired person at my primary and secondary school, and I had this feeling of being the odd one out! Once I had this being part of a group I didn't want to go back, to just being the odd one out. It put me in a weird place when I went home because I didn't know how to be anymore. I think there was this big elephant in the room and I just didn't know how to address it.*

Whilst this may be a common assertion, it is important to note the effects that a feeling of isolation can have on the development of a young person's identity around VI. There are many arguments against the separation of disabled people from wider sections of community in terms of segregated education and activities, but the importance that participants placed on the development of community as a factor within their maturation, is a significant aspect of the ways in which these participants engaged with their subsequent educational experiences in HE.

As Emily describes her experiences of being a disabled young person in education more, she views her journey in a positive way. Ultimately her move to attending a specialist educational provider proved positive in engaging her with a wider VI community of peers. This also offered the opportunity to discover more about both herself and about visual impairment. As Emily recounted,

*I needed to have long cane training so yeah, I decided to go to college as firstly my school didn't have a sixth form and then this caused problems with getting equipment and support as I would have to go through the whole process of getting a new statement (SEND) and I was going to have to get cane training and independence skills anyways.*

*So, we did some research and found the college, went for an open day and applied. We thought as we were going to need to apply for me to go somewhere it may as well be there. We thought I would get more out of it – independent living skills and mobility are a big part of the curriculum.*

*So, we applied got the funding, really good, got a lot of support, did all the independent living skills, learned a lot! I learned a lot in terms of working and to be fair, where I lived at home there wasn't a lot in terms of support, so it was often us that had to force the issue with funding.*

*College was a good place for meeting people my own age who were VI and learning from them and learning more about being VI.*

Emily notes here the importance of learning from peers, particularly in an environment which focussed on developing independence and confidence when travelling. The tone of her account is one of excitement recalling the expansion of possibilities for her future and her growing awareness and identity as a person with VI. What she describes is a renegotiation of identity influenced by peers. However, Emily also notes that there were issues with living away from her family, non-disabled peers and community in terms of socialisation within wider communities and society:

*One negative is that it is quite insular in the terms of being a special school, we don't have much to do with the outside community, so I lost touch with a lot of my friends, because, you know, everyone moves on and you don't really have a lot to do with the college community outside of school, that's a negative, it is a bit insular!*

*I feel like I lost a lot of the social skills when I went there, I wasn't really different to anyone when I was younger, then when I transitioned from college to uni, I struggled quite a lot with the social side because I had been in that environment for two years where I wasn't the odd one out. It was a harsh culture shock to go back to being the "blind one".*

Emily discusses how her separation from non-disabled peers and being contained within an environment which caters specifically for visually impaired people had, in a way, a detrimental effect on her socialisation and participation within wider society, whilst simultaneously embedding her within a supportive specifically VI community. Attending university was accompanied by a return to isolation and being labelled as other. Michalko (2002) discusses how he experienced his gradual changes to his sight across his life course, noting that as he approached and entered adolescence his blindness became more noticed amongst his community, stating that, similarly

to Emily that this brought with it a recognition that he was different, "I knew that I saw differently from how I used to see but now I was beginning to be noticed, and to notice myself, as different from others and this difference was making a difference" (Michalko, 2002, p.20). He recalls the ways in which the constructions associated with difference placed him on the margins of participation within his school and peer group and that ultimately a move to a new area and school created opportunity for change.

Emily notes that having been part of a supportive VI community created problems for her when she went to university, particularly with making friends within her student cohort, as her difference meant that interactions were largely only about that. This served to remove her from the wider student community and cemented her in an outsider position. Segregated education can be seen as emphasising othering and difference directly due to what might be considered its 'insular' nature. That this then interacted with constructions of VI in HE through being "the blind one", renewed a position of isolation for Emily. However, what Emily identifies strongly is that to pass amongst her peers and within her community is an identification of Self (Goffman, 1959). Michalko notes that this presentation of self is often a private, invisible action, although examining his own experiences he notes that "ironically my blindness makes the process of a defining a sighted self visible" (Michalko, 2002, p22). Similarly, Emily, when discussing her return from school and entering the higher education community as "the blind one", shows an acute awareness of the juxtaposition of blindness and sightedness. Within university and her home life, visual impairment, and so, Emily, is the anomaly, but in segregated education, she had been part of a community centred on the collective experience of visual impairment. In both cases the move into these different communities necessitated reviewing her sense of self, as well as resulting in a changing relationship with

independence. When Emily is identifying a subject position of being “the blind one” at university she is revisiting her position as anomaly amongst her sighted peers and community. Describing it as a “harsh culture shock” Emily is thus identifying higher education as rooted in an expectation that participants are non-disabled students.

This emerges in Naomi’s account as well, where the expected independence of university was also accompanied by isolation and the construction of the VI person as other. Discussing her move from a specialist segregated educational provision to university, she said that:

*For me, coming to uni after boarding school, where you are in a lovely little cloud, it is such a daunting thing. You are back in this mainstream world, where everyone has sight and a lack of understanding.*

Naomi highlights how boarding school can be seen as a very supportive environment but may create a misplaced sense of confidence. For example, at school all the learning materials were provided in a range of accessible formats and using a range of approaches, whilst in university there was a constant battle to ensure materials were accessible. Naomi further commented that from her perspective as a university student, “*people were within the little cloud of school*”, suggesting that it might be seen as a dream world, as in some way illusory.

Naomi’s comments on university involve reflecting back on school and college, so drawing on her experience of several versions of pre-university education. This shows how constructions of the VI student need a wider context to be understood effectively. She also identifies how differences between school and university can have an immediate effect upon the individual learning experience. In her case, similarly to some of the critical incidents described by others, the onus



was on her as an individual to find a solution rather than a solution emerging from part of the structures of support within the university:

*I don't think there was a disparity because I had been in mainstream first and then went back in uni, I didn't ask for things in large print or large print books, I had a CCTV and did it all myself. I knew I wasn't asking for the earth, but the ignorance is astonishing! The uni didn't even know how to make the font bigger on hand outs, I was like all you need to do is highlight it all and make it bigger and they were like nope, can't do it. I felt like there was no hope! I even went to the equality and diversity team that first year but then I just did it myself.*

Naomi's struggle regarding accessibility is emphasised by her negative language and repeated references to taking the initiative. She had sought independence in the sense of independent living, as had the other participants, but was confronted by a different kind of independence in having to ensure accessibility to the curriculum. It is possible that the personalised support given within segregated education partly caused her struggle. Involvement in an environment where provision is individualised and, regardless of the negativity associated with segregated education, is suited to individual requirement can and does create expectations. The subsequent university provision proved to be much less individualised and demanded that Naomi change to suit the environment. The construction of an identity as a VI HE student involved considerable work to develop and maintain in the face of problematic structures, attitudes and assumptions within HE, particularly regarding the ideal student. Whilst taking responsibility for one's own learning is part of learning at university the ableist construction of the student means that Naomi and the other participants had to do a considerable amount to achieve what might be seen as a level playing field within HE.

### **Passing**

The concept of passing emerged in several accounts but is particularly relevant in Emily's as she discusses how she moves through differing identities,

both as student and as VI student, as she negotiates her world. She is also conscious of the sometimes-acute differences between her perception of herself and how others view and construct her. Participants experience many dualities in relation to this. As Emily says,

*I really like make-up and stuff and I feel like part of that is me taking back control of the situation because people don't expect me to be able to do my own make-up, people don't expect me to be able to dress nicely and it is awful. I hate that I feel like this, but I always feel flattered when someone says, "oh you don't look blind". I think that is a compliment cos I am aware enough to know of course it isn't a compliment, but they mean it as a compliment and it feels it as a compliment cos it feels like looking VI is a bad thing, which is what they are inferring that looking blind would be a bad thing so therefore not looking blind is looking good!*

Emily discusses what she conceptualises as "looking blind" based upon the assumptions of others about the ways in which blind people are expected to look, how they are expected to dress and what they might wear. These are shown by the comments about not looking blind, which Emily feels is a negative construction of people with visual impairment. Her refusal to become what others expect are shown in terms of her use of make-up and the wearing of clothing which she feels is not typically expected of visually impaired people. As Michalko (2002, p.149) notes in relation to this concept of passing in public, "I conduct myself in public with the knowledge that I am visually available to others, and so I dress appropriately... I use phrases such as "See you later," "I watched TV," "I saw that movie" and so on.... 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". Emily's account indicates a similar engagement with passing, although focusing more on appearance than language. She also notes her ambivalence about compliments and how they are based on negative assumptions that position visually impaired people within a stereotypical construction, one located as antithetical to that of the ideal

student. Emily continues with this theme, pointing to her presentation of self as a feminist assertion and as a challenge to her construction as other, showing an awareness of how being female, feminist and disabled interact in her identity as VI student.

*Yes. I don't really know what it is to look blind, apart from stereotypes. It is a totally backhanded compliment anyways! I don't know what it is I am supposed to look like! That is one of the ways in which I take back control and you are thinking from a feminist perspective there is a contradiction where I don't really fit in with all the feminist rhetoric either, for me a lot of this is misogyny and being objectified, which I don't think I have experienced in terms of being a disabled woman. It is, for me, the opposite!*

*...you are not objectified to such a degree that no-one thinks of you as a sexual being, at all. well I don't fit in with that feminist perspective either, so then you have this conflict where I am a feminist and I don't want to be objectified but then I do want to be a little bit cos I want someone to acknowledge that I am and it's really confusing.*

Emily is aware of the contradictions in both wanting to be admired and simultaneously rejecting it. She also notes that aspects of feminism, as she understands it, do not apply to her due to how being female and disabled intersect. Her feminist principles suggest that it is unwelcomed to be objectified, and whilst not wishing to be objectified as a woman she feels that it is difficult for her to draw upon feminist oppositions to being objectified as a disabled woman. She indicates that two very different forms of objectification are connected in her statements. Emily states that she wishes that her objectification could be acknowledged on its own terms rather than being inextricably contained and subsumed by her disabled identity. Emily's feminism functions in two ways in her life. On the one hand it offers principles with which to understand her world and act upon the things she experiences, on the other it offers a form of relief from elements of her identity.

*In a lot of ways, feminism is a way for me to identify with a group which isn't disability related, it's kind of a relief I belong to a group that has nothing to do with my disability, but at the same time it is something I feel strongly about and something I believe in.*

For instance, Emily talks about the ways in which her disabled identity and her feminist principles are linked in her discussion around her life with her partner, who is also visually impaired. She identifies that gender intersects with disability in different ways, both in how she and her partner are understood by others and in terms of self, noting:

*I think there is a thing about being a woman too, I won't ask for help, my boyfriend will. I won't. he does! My confidence has gone up 'cos he doesn't think twice about asking a stranger in the street for help and to him it's not a big deal and it kind of challenged my way of thinking well why is it such a big deal for me! That is part of it - I don't want to ask anyone for help ever cos it makes you look weak.*

Emily summarises how by asking for help she feels that her subject position is weakened. Emily's acknowledgement of the stronger position she feels that her partner maintains, in interactions with others, has led her to question why she feels asking for help places her in a diminished state of being. What she asks herself can be understood in the light of what Goodley (2016, p.34) argues regarding how disabled women "occupy a specific site of exclusion" and can be seen as related to the ways in which women within society are expected to behave and act and their continued exclusion from a patriarchal ableist society (Goodley, 2014, p.49).

Throughout our discussion Emily expresses the frustration she feels about other people's reactions towards her drawing examples from her everyday experiences. Her confidence and sense of self are affected by their construction of VI and she is very aware of neoliberal conceptions of her as worthless. Her comments also suggest how difficult it is not to internalise these negative constructions.

*It undermines your self-worth as a person 'cos the kind of the way I feel is that you are constantly made to feel, or it is suggested that you should be*

*grateful for what you get as a disabled person or as a visually impaired person, but you can't talk back cos you should be grateful.*

*Like how dare you bitch and whine about what you are getting cos you are such an inconvenience and people are going out of their way to make accommodations for you that you should take what you are given and deal with it.*

As Emily has shown here, these constructions stem from conceptions of disability and are set at the intersection with participants' experiences of youth, disability, visual impairment, expectation and the ways in which these both shape and inform their lives both inside and beyond HE.

Ableist assumptions about disabled people and relationships often lead to reactions that marginalise disabled people when they are viewed as doing something that challenges a normative construction. As the narratives various participants have shared indicate, this includes being a student in HE. Maintaining confidence and an identity as a student in HE who is VI takes a great deal of work, as the accounts suggest.

In conclusion, as this chapter shows, how visually impaired people perceive their involvement within wider society is replicated within the structures and perceptions present within higher education. In addition, identifying oneself as an HE student, and VI, troubles assumptions about disability and may be reacted to in unpleasant ways. How visually impaired people experience their day to day lives is imbued within negative constructions rooted within ableist constructions. Participants, through their insightful telling of their experiences, identify that their lives are constantly under scrutiny within wider society and that this has an impact in various ways upon their lives within higher education. Contradictions abound in trying to negotiate relationships with university peers, and in the interplay between independence and dependence that they are positioned in by university structures,

all coloured by assumptions about their competence and vulnerability. Further, the impact of constructions of them as worthless, or as expensive or spoilt nuisances, as a number of the accounts outline, also make university a challenging arena with their very engagement with HE positioned as problematic.

Emily usefully summarises how these factors impact in many, varied ways and ultimately reveals that the experience of being a visually impaired person is laden with negative and ableist assumptions and actions which are replicated and replayed across the spectrum of experience.

*Then it seeps into different parts of your life, it disables you in different ways. It disables you from being able to express your opinions or desires, it disables you from being able to stand up for yourself, it disables you when it really matters. It impacts you in everyday interactions, it's not just you being as a disabled person and a disabled body it's you as a person, and the way you are made to feel.*

Consequently, what is experienced in higher education is often a direct result of the ways in which visual impairment and disability are constructed within current and historical temporal and liminal spaces.

## **Chapter Seven: Conclusion**

The experience of visually impaired students in higher education, as this thesis suggests, is one that is often negative. Whilst some of those who took part in the research successfully completed their studies and all reported that there were positive experiences, especially about getting to grips with their discipline, any success seems to be despite the structures and services that were intended to support them, not because of them. Their accounts indicate that despite claims regarding inclusive education, practices and attitudes in these institutions, especially in the light of neoliberal constructions of the HE student, remain in tension with them as visually impaired students in ways that have an impact upon their experiences and identity in HE.

Visually impaired students make up a small percentage of the numbers of disabled students in higher education more broadly. There are indicators of why this may be suggested by the experiences outlined and discussed within this research. Higher education is positioned as a transformative and inclusive environment, but the structures for support, and indeed many elements of the student experience contain deep-seated ableist notions. Visually impaired students face a double bind of inherently ableist tensions of which the first aspect is contained in their day-to-day interactions outside their participation in HE. These impinge significantly on their routes into, and beliefs about, participation in higher education. Previous education in school or college, of course, also informed their views and expectations, as their narratives confirm. The second aspect of the double bind comes into play on entry to HE, where the staff and systems they encounter frequently display tragic and disabling attitudes towards visual impairment generally, and their actions consequently colour the participants' experiences. The participants found navigating another arena heavily loaded with negative constructions to be daunting.

Given the scale of the research, it cannot make a generalised claim about the experiences and identity of all visually impaired students, nor can it map their prevalence. It also cannot conclude that all institutions in HE have a similarly problematic approach to the participation of VI students. However, the research does suggest that many aspects of study at university are problematic and that this negative experience is not attached solely to study at a single university, something also suggested by the HEFCE (2017) report. What this thesis has done, informed by Critical Disability Studies, is examine the experiences of visually impaired students from a uniquely combined standpoint of experiences as a student and their experiences, more broadly, as a visually impaired person. Where previous literature exists, this tends to centre on experiences solely within higher education, particularly about study itself, rather than drawing on the participants' accounts of everyday life to understand how visual impairment is constructed, understood (or not) and correspondingly, how visually impaired people feel about and experience their lives.

The chapter is broken down into sections that relate to the preceding findings and discussion chapters. It also contains recommendations for areas of HE practice drawn from the findings and discussion, and suggestions about the potential for further future research in this area and related topics.

### **Reflecting on the purpose of the thesis and the unique contribution to knowledge**

As stated, this thesis has explored the tensions experienced by visually impaired students as part of their higher education experience. Through analysis of the interview material and of the further discussions with participants that built on our initial interactions, it became apparent that incorporating experiences from outside the immediate experience of learning in higher education was important. Through the participation of these additional areas of experience the participants'



narratives indicate that they informed each other, and that HE was often simply another problematic terrain. Consequently, every day interactions getting to university and earlier educational experiences became important indicators regarding the HE experiences and of how the constructions of HE and VI exist in tension. Indeed, it can be argued that HE works to expel students with VI through disabling practices, whilst simultaneously offering access and a limited amount of physical support.

This additional input means that this research offers a more holistic understanding than other studies, such as Hewett *et al* (2017) and Fuller *et al*, 2006, that have focused solely on experiences of learning within higher education. The narrower focus of these articles certainly illuminates specific areas of experience, but taking a broader approach enables links to be made across what might be assumed to very different spheres. In addition, the only similar research, that by Bishop and Rhind (2011), whilst it does touch on concepts like the idea of positive perspectives regarding visual impairment on the part of participants, has also a learning specific focus. It is also centred on a single location, unlike this research that draws on a number of different campuses, indicating how spatial issues impact upon the experience of HE for these students. Thus, the conclusions of this thesis have potentially more impact and possible uses than research solely examining the concept of being a visually impaired student.

Therefore, this research offers a unique contribution in that the exploration of a collective experience of university and everyday life offers a distinctive approach, which, combined with a critical, intersectional, ableist approach, is not replicated within contemporary literature and research.

In relation to what this offers to disability studies theory the knowledge provided by the retelling of participants experiences illuminates the ways in which

disability as deficit and as difference is reinforced within interactions with professionals and society wide. However, in addition and far more positively in terms of moving forwards and offering unique insights, this research provides substance to existing theoretical positions. It also strengthens further the argument for additional research. It also indicates the need for theoretical underpinnings which take at their core a commitment to intersectional approaches which not only examine visual impairment, a concept which is under-explored in this context, but also that of the experiences which also may make up identity as a disabled person, such as race, gender, age and cultural experiences. This is crucial in the ongoing development of disability studies theory.

### **Revisiting the research questions.**

#### **In what ways do the paradigms and constructions of visual impairment and higher education intersect and interact?**

As indicated in the literature review and in the aspects of the participants' experiences of what could be called the marketing of the university, HE as an arena is presented as accessible to disabled students through policies and practices aimed at breaking down barriers to participation that are experienced by disabled people. The participants detailed aspects of their lives as visually impaired and a student showing how policy affects their acceptance within the arena of higher education. Whilst these policies offer some challenge to inequality, their impact is relatively small in the participant accounts indicating that higher education is often exclusionary. What the experiences of the participants within this study demonstrate is that at least some HEIs replicate, rather than address, the wider inequalities and exclusion of disabled people, so meaning that the paradigms of VI and HE intersect and interact in problematic ways.

Drawing upon Goodley's (2014) examination of the ideal citizen as a conceptual lens I have explored how the institutions these individuals attended adhere to a corporeal standard of personhood which positions disabled people as outside the expectations of the ideal. In this they reflect wider society. I have discussed how Mingus's (2011) 'mythical norms' underpin the standards of personhood that are valued within society, such as being engaged in meaningful employment, participation in activities and making autonomous rational choices. For visually impaired people the corporeal standard, perfect, species-typical, essential fully human, body as discussed by Campbell (2009) is unobtainable given these concepts are rooted in conceptions of ability, perfection, health and being non-disabled. Where disabled people are unable to achieve these standards of personhood, as they require additional resources, or cannot find gainful employment, their value and worth is diminished. Further, in this research there is some evidence that the intersection with gender means that some disabled students are more valued than others. Male participants, and older participants, for example, were constructed as less 'diminished'.

Within higher education, these notions of the corporeal standard can be seen as simply adapted into a figure who can be characterised as the ideal student. This student is one that requires little intervention and is one that can engage with the commodification of higher education and with it as a means with which to seek material gains in terms of employment, income and status. The rewards of doing so are understood as a successful life, defined as one free from dependency.

As higher education is increasingly expected to produce work-ready future employees and traditional notions of education as a means with which to develop one's self and one's society are suppressed by the philosophy of neoliberalism, visually impaired students face a tension. HEIs argue that they are accessible to all

and are influenced heavily by directives and policy aimed at improving social mobility, yet they seem more explicitly linked with financial reward and conformity. This can be considered to be combined with the low collective value of visually impaired students within contemporary society. Because of these two factors, VI students run the risk of becoming further excluded by the higher education sector. If HE in general continues a trajectory that incorporates neoliberalist guidelines and acts in line with market forces and thus cannot genuinely incorporate diverse lives and diverse goals, then the question becomes to what extent visually impaired people can participate, indicating an interaction that is either dismissive or excluding.

Examining how the paradigms of visual impairment and higher education intersect and interact draws parallels between HE and how visual impairment is constructed within wider society as a personal tragedy, or through the lens of medicalised definitions. The participants' accounts emphasised that identifying as a visually impaired, disabled student, requires medicalised assessments to set out the parameters of support. Without this, students are unable to access technology and adjustments that could and do facilitate their participation. Therefore, from the outset, students are constructed as in need of medical and rehabilitative practices that present visual impairment as problematic. When the value is placed firmly on the expert knowledge of assessors and others within the process and not on the expert knowledge held by the visually impaired person this draws heavily on ableist notions of disability and impairment. Where visually impaired people require adaptations, in depth support and assistive technologies, the way that this is put in place is heavily directed by expert knowledge held by people in positions of power, typically without direct experience of being visually impaired.

That the support and assistive aids made available are typically decided on by assessors rather than by the visually impaired person leads to a tension whereby

expert knowledge usurps the knowledge of visually impaired people that is rooted in experience. Through these assessments, visually impaired students are positioned from the outset within a difficult and disabling rhetoric about their participation in higher education. To participate requires taking on board the role of disabled student, something that brings with it negative and disabling discourses of difference and value. Externally prescribed mechanisms, then, 'allow' participation that is bounded within ableist notions of the ideal, neoliberal citizen and the ideal student.

Whilst this appears to be at the behest of those who are involved within the practices which visually impaired students are required to participate in to gain access to higher education, it is apparent that this rhetoric and practice are drawn from wider society. Similarly, to how and where common-sense ideas about disability and disabled people permeate daily lives and experiences, these also permeate the experience of visually impaired students. The research shows that whatever claims are made by or on behalf of HEIs, the participants' experiences indicate that the sector is in line with what happens in daily life as a visually impaired person. Participants have drawn strong links between their experiences within wider society and HE, thus showing how ableist and disablist discourses pervade their lives and how they impact upon participation.

When visual impairment and disability are constructed as a problem within HE, then there is no true interaction or communication between student and staff within the institution. The paradigms intersect, but in ways which routinely position VI students as demanding or troublesome regarding resources and time. The space and discussion are dominated by professionals and services, both of which demarcate the ways in which those considered to have a disability populate these

structures and determine how impairment must be tackled and managed. Of course, this is not to say that all staff engaged in these roles are limited in their understanding, but the accounts do suggest that training, at the very least regarding awareness, may be needed in many HEIs. These students are also situated as needing expert knowledge and work to tackle and, in effect, overcome their disability enabling them to function as an ideal student, constructing them as in deficit.

### **How do visually impaired students construct and describe their identity within Higher Education?**

Examining visually impaired student's identity within higher education has highlighted the complex, intersectional components existent within people's lives. In addition, what this has identified is the constant state of flux that disabled people experience in their lives. The concept of identity is drawn from individual perceptions about who that person is, a daughter, a son, a mother, a father, a student, a disabled person, visually impaired and so forth. However, for visually impaired people their identities are also located within ableist constructions of disability as deficient, poor, ill, deviant, unvalued. These constructions are forged by the ways in which society values (or not) disability and difference. Disabled students from the outset of the HE experience are positioned within a medicalised, and deficient model of disability where admittance relies on 'coming out' as disabled and taking on board the constructions associated with that, something which changes, as the participants suggest, their sense of identity. This assessment is rooted in a medicalised view that positions disability and impairment as an issue of the individual, not the institution or wider society, and so disabled students who require adjustments are located within a rehabilitative framework. To participate requires the disabled student to 'accept' aids and adjustments to be able to participate like other non-

disabled students. This identity is one that is linked to any student who goes through the process as a disabled student and remains throughout their academic career.

Whilst without adjustments and aids visually impaired students may find it hard to negotiate and participate in higher education and thus there is a financial justification to providing evidence that individuals are suitably disabled to access them, taking an alternative, student led approach tells a different story. This would move notions of identity away from regarding oneself as a visually impaired student, and towards being simply, a student. Additionally, access is different from this standpoint. The participants articulate an argument through their interviews that diversity is to be expected. Rather than negotiate tricky and ableist notions of access that attempt to change the person to fit the environment, their interviews suggest changing the environment, whether that be in relation to accommodation, the campus, or modes to teaching and learning. This would reflect the diversity within broader society and would be beneficial to a number of groups of students as well as visually impaired students and disabled students. Such groups would include; parents, those who must work alongside education to support themselves, international students, and those with caring responsibilities.

In addition, as universities are required to diversify because of increasing political pressures, a shift towards more inclusive practices from the outset may be apt. As yet, however, the participants' experiences suggest that whilst there are claims made by HEIs about diversity, the reality is more excluding than inclusive. The accounts indicate that fellow students are also informed by ableist notions, as is evidenced by the othering described by the participants in some key incidents. Here too there is a suggestion that the VI student is not understood, or respected,

as equal to other students, although factors such as age or gender may change the level of understanding.

What participants' accounts also suggest is that visually impaired students offer a challenge to higher education in that their attendance at university makes visible to the institution overarching ableist notions about who should and does participate in higher education and the reasons why they do. In addition, these students give evidence of resisting practices rooted in medicalised, ableist dialogues that appear under the banner of participation. Their navigation of ableist notions about the places and spaces that disability should exist within, troubles the common sense and disabling practices inherent within education. Whilst external factors such as these notions often construct perceived identities of visually impaired students, how the participants within this research have raised a challenge has been to make apparent their perceptions and understanding about how they are envisaged by those within their HEI. By laying out what disabling practices and expectations they encountered, and discussing their responses, these visually impaired students are offering unique insights into tackling the beliefs that underpin their interactions with HE.

**In what ways is the concept of participation played out in relation to accounts of the experience of visually impaired students in HE?**

Whilst participation in higher education is often discussed in terms of ensuring that disabled and other marginalised and under-represented groups can access higher education, what participation looks like in terms of practice and how it is experienced has been shown to be convoluted and complex, with varying degrees of success, applicability and suitability. Where students are expected to engage with other people's expectations and decisions about what they might need



in terms of resources there is often a lack of suitable options offered. Participants' comments indicate that there were differences between courses and universities, but all noted that little notice was taken of the requests of the individual student and that where assessments took place, decisions were made that only drew upon the expert opinion of the visually impaired student as a tokenistic gesture. Visually impaired students are the experts in their own lives and the analysis of the accounts suggest that by ignoring their experiences and knowledge adjustments were often unsuitable and unnecessary and which were often wasteful and detrimental to their learning experiences. Changes in VI over time were also a problem for the services of HE, for, as the allocation of support at the start of study suggests, there was a misunderstanding of what VI might mean, which could be said to be attached to a stereotype, the 'hypothetical blind man', a figure who is changeless.

Furthermore, where students offered a challenge to the homogenised assertions about visually impaired students such as those played out within support relationships, or in relation to course materials and attendance at lectures, their expertise in their own lives was ignored and their knowledge about their own learning and living needs disregarded. participation, therefore, appears as a tokenistic gesture, rooted in ableist knowledge about disability. This approach to inclusion is also an issue for how resources are managed in universities, as it tends to generalise, and so allocate what is assumed to be needed, not what might actually be useful.

Participation is a thorny and often unsubstantiated claim regarding the involvement of disabled people within education and this research highlights how the premise of inclusion is one that is applied by others to the lived experience of being disabled. More importantly, practices are unlikely to be truly encouraging of

participation when those positioned as expert are not knowledgeable about visual impairment, or who take a 'one size fits all' approach concerning impairment and adjustments. This lack of encouragement of participation is then amplified by a want of awareness on the part of non-specialist staff within institutions.

Participation then, in its truest form, could remove the physical, material and ableist barriers to HE. Higher education, as an arena rooted in the promotion of education and discussion and knowledge production is an ideal place to create environments that are more inclusive and tackle the division increasingly played out in neoliberalist agendas within higher education policy. Both day to day experiences and critical events show the impact of the lack of participation upon their student life. For example, as demonstrated, issues around travelling to and from university when your accommodation is unsuitable, or where you have not had access to support to travel to and from the campus, adds additional stress and requires complex solutions. These pressures required the participants to take more time and make more effort to find solutions to problems that their non-disabled peers do not face. Participation, then, is also addressing and acknowledging the additional 'stuff', whether that be materials, or physical access to HE, that is part of being VI and a VI student.

### **Implications for practice**

#### **Students**

Research such as this, centred on the voices and experiences of individual VI students, acts as a counterbalance to other types of account that either medicalise, or demand change. The focus on individual experience is not intended to replace collective action, but, perhaps, to inform it. Furthermore, and more importantly, this account contributes to the small body of work that addresses visually impaired students' experiences. These are underrepresented in much of the

literature, particularly in relation to the ways their lives intersect and interact with the constructions of visual impairment within contemporary society. The voices of these students also indicate the significance of intersectionality in accounting for their experiences.

Visually impaired students do engage with peers on networks established on social media and through education and leisure opportunities. However, these are informal spaces, and this alternative or additional provision should remain entirely separate to these to ensure that these networks are solely for the people that use them. Whilst they could be employed as a way for services and institutions within HE to gain a greater understanding of VI students, appropriation of these by other groups, or for other means than the provision of a network that is led by and for students would be a disabling process which takes away their autonomy. As noted, I felt uncomfortable having encroached on these networks, even indirectly, in locating participants in this research. What the existence of these networks, combined with the accounts of the participants, suggest is that at least some VI students might welcome some form of formalised buddying systems in universities, separate from support services, particularly in the earliest stages of study.

The research also suggests that student voices need to be acknowledged much more. Visually impaired students have, understandably and rightly, much knowledge about being a VI student within education, often from an early age, although of course this depends on individual circumstances. HEIs should access this experience and knowledge, as well as that of alumni, to create future provision, whether through engaging with research such as this, or through less medicalised engagement with current students. Additionally, it is possible that visually impaired students themselves will draw upon what has been found within this research to

support their decision-making or to tackle disabling practices within HE, or even within education more broadly.

### **Higher education staff**

Whilst HE in general replicates the wider inequalities associated with being visually impaired, there are important contributions made by those who work directly with visually impaired students and also those whose research engages with their student experience. Many of those cited in this research, such as Bishop and Rhind (2011), recognise that whilst it is difficult to alter the existing constructions associated with disability, it is nevertheless crucial that those working with visually impaired students engage with students to explore their own expert knowledge about their lives. It is impossible to generalise across all staff and suggest that this does not already happen, however it is apparent that in many of the instances discussed within this research that the interactions with support and university staff often do not, or cannot, take on board the student's own knowledge, expectations and desires for their experiences. Whilst not unsurprising this remains concerning. Opening up the space for discussion at the first instances of application and enrolment is vital to create a higher education arena that is truly inclusive and one that is led by student experience. By doing so, visually impaired students will access higher education in a manner which is directed by their own requirements, allowing the student autonomy over their student experience. In the long term, this will help to create a cultural shift towards participation based on disabled people's choices over and above the existing rhetoric of neoliberalism and the ongoing, deepening move towards higher education as method for the improvement of social mobility.

Additionally, whilst there remains a lack of understanding about visual impairment it is difficult to foresee any immediate changes to the experiences of visually impaired students given that the construction of VI is rooted in a rhetoric of

confusing and limited discourses. Creating mechanisms that enable both students and staff to share good practice and knowledge could overcome many of these challenges. Changing the ways in which staff, whether services or academics, are working with visually impaired students is a practical and relatively easily resourced change. Bringing together students of services within the university could also provide highly useful and practical solutions. Students sharing experiences of good practice or explaining what their requirements are as practical steps to ensure that assessments are focussed on the expert knowledge the student holds about their own lives would be beneficial to the student, make the financial costs associated with DSA more efficiently used and improve the provision that is available to all students. Where the step changes are made, such as a student led assessment process, and dissemination to other departments within the university, for example, other students will benefit also. This, in turn, will benefit the university as it manages expectations and limiting financial circumstances associated with the current time.

Support services within this current research had a great impact on the quality of the student's learning experience. It was also apparent that where support services were not aware of or did not appear to understand the visually impaired students' needs and how these differ exponentially from student to student, support and participation were significantly impacted upon. Often this was tackled, as the accounts state, by individuals repeatedly seeking recourse by revisiting the support services, although some required support from lecturers, or family, or outside agencies. The analysis suggests that having the opportunity and means to encourage individual, student led, plans for support would much improve matters. Such support could and would be reactive rather than prescriptive and accordingly would be more including of individual preferences and requirements. Furthermore, support workers could be more able to provide support if directed by the student, as

they typically have little specific training and may have limited prior experience. Consequently, this process would have a number of benefits for the student, as well as to staff. Particularly when it is apparent that HE seeks to fulfil much more than simply providing a higher education.

### **Policy and higher education organisations**

Policy objectives in HE makes many references to the development and improvement of inclusive practices and social mobility particularly in relation to disabled students and other ‘marginalised’ groups, as noted in earlier chapters. Whilst, arguably, these aims are altruistic and linked to ensuring fairer access and equality of opportunity and practice, this research has highlighted, alongside other relevant research, such as Fuller *et al* (2006) and Bishop and Rhind (2011) that there is not always a practical application of these policies. Further, the experiences of research participants suggest that practice continues to remain rooted in ableist and ultimately disabling assumptions.

What this means for the broader policy directives within HE is that there ought to be a commitment to engaging with visually impaired students, moving away from a top down approach. The first step towards doing this, or establishing a better foundation for it, would be to not have such broad categories relating to statistics around disabled students. As noted earlier, the lack of data may contribute to a lack of engagement. A bottom-up approach could potentially benefit many: the staff working with policy directives, academic staff teaching and researching within these areas and ultimately, and most importantly, the students within the system. If, as older policy states, students are at the heart of the system, this approach takes on a commitment to moving away from rhetoric and genuinely making students central. What this should not mean is that students are at the heart of a system that intends participation within to be the moulding of disability to a malleable, pliable and

individualised experience, but one that is readily present and welcomed as a diversity that is to be expected and respected (Cameron, 2014) and which shapes higher education from the ground up.

Whilst there are projects carried out by many organisations and academic research around the topic of disabled students, and on a smaller scale, visually impaired students, it is questionable how much impact these have on policy formation. Whilst the introduction of the OfS may represent a sea change, there is little evidence, possibly due to the relative infancy of this office, that it has the voice of students embedded within its practices and objectives. Whilst disappointing, this also is frustratingly common. As this research has shown, visually impaired students are the best ambassadors for their participation within HE and architects for future generations. When individualised, tragic conceptions of visual impairment are unwanted, and collectivising of experience shows and welcomes the diversity of the population, this politicises and troubles inherently disablist practices and attitudes. However, it is crucial that this does not become a tokenistic gesture.

As is detailed across this thesis, where legal obligations are mostly met and guidelines often followed, what often is discussed is a lack of consultation and thus sharing of expert insider knowledge which may afford more positivity and satisfaction amongst participants, particularly where support staff are usually highly qualified and skilled practitioners who likely share best practice and offer a buffer between top down policies and the experience of the individual student. This appears to result in a tension between policy and practice.

What this research offers in terms of contribution to knowledge in relation to disability and higher education and specifically with regard to visually impaired or blind students is a deeper exploration of the multiplicities which occur in their lives at the time of being a student and which are drawn from previous experiences and

which, in likelihood could impact on future experiences. What this tells us about the experience of being disabled in HE is that whilst there are significant changes to the ways in which disabled people are experiencing HE there is often a long way to go. This does not always rest within the domain of practitioners, or those implementing policy, as many appear to be attempting to seek and employ means with which to challenge negative connotations. However there remains a necessary challenge for those who work, study or have policy interests within HE in ensuring that disabled students are a crucial voice within the discussions about how HE should evolve and how disabled students, and particularly in terms of the focus of this study, visually impaired students, can be part of that. Higher education, as discussed within this thesis, seeks to fulfil many different and sometimes conflicting roles, and as those involved develop the offer of HE in future it is imperative that discussions around participation start with disability but do not end with it.

### **Potential for future research**

Finally, future research and practical projects could build on the suggestions made in this thesis in relation to changing how HEIs understand VI and support VI students. What this could also contribute to is the development of strong leaders in research drawn from the diverse communities that make up our student populations.

Future research by both myself and others engaging with visually impaired students, could take a number of forms. Higher education statistics often link together students with two or more impairments, so there may be many more visually impaired students not delineated within the statistics whose voices are not yet heard. Whilst individuals may not wish to be identified, more accurate figures would help to justify future research.



To further build on this thesis, it would be possible to engage with Participatory Action Research led by VI Students investigating and exploring aspects of their lives that they feel are of interest in understanding the student experience. Additionally, it could form part of research projects involving these students in developing new and innovative ways of ensuring higher education policy is inclusive of their voices and experiences.

Also, there is scope for exploration of the experiences of visually impaired students as they transition from statutory education into higher education, as this research suggests. This could be beneficial in several ways. Firstly, it could support change in terms of practices within HE, particularly around support and retention. Further, it would simply expand the data available on the differences between their experiences in education prior to HE and how this differs from HE. As this current research has highlighted there is a range of expectations and practices within statutory education and HE, which whilst unsurprising, is nonetheless a key theme which students themselves brought up to explain and explore their experiences in HE.

Another potential development is research that incorporates a focus on shared learning between support services and higher education institutions directed by visually impaired students. Such work is likely to offer a unique and timely development. Given that student support services are dealing with growing financial and other limitations and higher education as a sector is facing seemingly constant change, it is increasingly important that people involved within this sector, whether students, academics or support staff are able to work together on issues of participation.

Finally, drawing on themes within this research, future projects could include an exploration of the ways in which other disabled students experience their time

within higher education, again drawing on their daily life experiences. The collectivising of experiences which politicises disabled people's individual experiences, as this research has suggested, is vastly important given the continuing pressures faced by disabled people regarding access to increasingly dwindling resources; mounting pressures on welfare systems to encourage claimants away from benefits and welfare payments; and the expectations of a society which values financial autonomy and employment.

## **Appendices**

### **Appendix One. Participant Information Sheet.**

## **Constructions and Paradigms in Tension: Visually Impaired Students and Higher Education**

### **Participant Information Sheet**

You are being invited to take part in this research study. Before you decide it is important for you to read this leaflet, so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

#### **What is the Purpose of the Study?**

The purpose of this study is to explore visually impaired students' experiences of higher education; to understand what goes on in the general interactions that occur surrounding a visually impaired student at university. Additionally, the research aims to investigate what inclusion means for a VI student and how VI students respond to the attitudes and experiences which are present in higher education.

#### **Why have I been invited?**

It is important to seek a broad range of visually impaired student's experiences, to gain a good understanding. You have highlighted your interest in participation because you have identified as a visually impaired student, currently studying in higher education who might be interested in taking part in this study.

#### **Do I have to take part?**

No. It is up to you whether you would like to take part in the study. I am giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why. You are completely free to decide whether or not to take part, or to take part and then leave the study before completion.

#### **What will happen if I take part?**

You will be asked to participate in two data collection methods:

a one-to-one interview with me at a mutually convenient location and time; A follow up interview at a place and time of your choice where you can discuss aspects you feel highlight your experiences of being a VI student in higher education

You will have all processes explained to you, including confidentiality, information storage and dissemination, withdrawal and offered a short debrief at the end of the research. You will need to be willing to consider the questions posed by me regarding your experiences in higher education.

### **What are the possible disadvantages of taking part?**

The possible disadvantages in taking part are that this will involve you being willing to give up some of your own time to participate in the activities mentioned above.

There may be questions which remind you of potentially difficult or upsetting incidences related to visual impairment or experiences within higher education. A risk assessment has been carried out. Opportunities for additional support after the interview process will be offered, in case you find any part of the interview process or the retelling of your own experiences stressful, upsetting or traumatic and any issues can be discussed in the participant debrief at the end of the interview. Specific information will be made available for you, should you require it, relating to accessing experienced counselling you through university such as the wellbeing and support services and information relating to external counselling services such as those provided by the NHS.

### **What are the possible benefits of taking part?**

The views of visually impaired people about their experiences of being a student at university are often under-represented when talking about disabled student's experience. Without knowing what it is to be a visually impaired student at university it is difficult to know if the provision available is useful.

### **Will my taking part in this study be kept confidential and anonymous?**

Yes. Your name will not be written on any of the data collected; the written information you provide will have a pseudonym of your choice rather than your name. Your name will not be written on the recorded interviews, or on the typed up versions of your discussions from the interview, and your name will not appear in any reports or documents resulting from this study. The consent form you have signed will be stored separately from your other data. The data collected from you in this study will be confidential. The only exception to this confidentiality is if the researcher feels that you or others may be harmed if information is not shared.

### **How will my data be stored?**

The typed-up transcripts from your interview and your consent forms will be kept in locked storage. All electronic data; including the recordings from your interview, will be stored on the University U drive, which is password protected. All data will be stored in accordance with University guidelines and the Data

### **What will happen to the results of the study?**

The general findings might be reported in an academic journal or presented at a research conference and will be represented within my doctoral thesis. The data will be anonymized and you or the data you have provided will not be personally identifiable. I will provide you with a summary of the findings to all participants from the study if you email the researcher at the address listed below, unless you wish to opt out from receiving this.

**Who is Organising and Funding the Study?**

Northumbria University.

**Who has reviewed this study?**

**The Faculty of Health and Life Sciences Research Ethics Committee at Northumbria University have reviewed the study in order to safeguard your interests and have granted approval to conduct the study.**

**Thank You.**

## **Appendix Two. Interview Schedules.**

### **Interview One -Interview Guide**

Tell me about your experiences of being a VI student?

Tell me about how you think about yourself as a VI student

Tell me about your perceptions of participation within HE?

Still thinking about higher education, do you think participation a reality in your experience?

Tell me about how you feel other people around you think about participation?

Tell me about your perceptions of the messages about visual impairment/disability that circulate in the HE environment?

Tell me about how you respond to those messages?

Can you tell me about any experiences that you feel really shaped your time at university?

### **Interview Two – Interview Guide**

Please can you tell me about what being visually impaired means to you?

Please can you tell me about what disability means to you?

Please can you tell me about when and how you became aware of what visual impairment is and what it meant for you?

Please can you tell me about when and how you became aware of what disability is and what it meant for you?

Please can you tell me about how you experience visual impairment on a daily basis?

Please can you tell me about how you feel people perceive you as a visually impaired person?

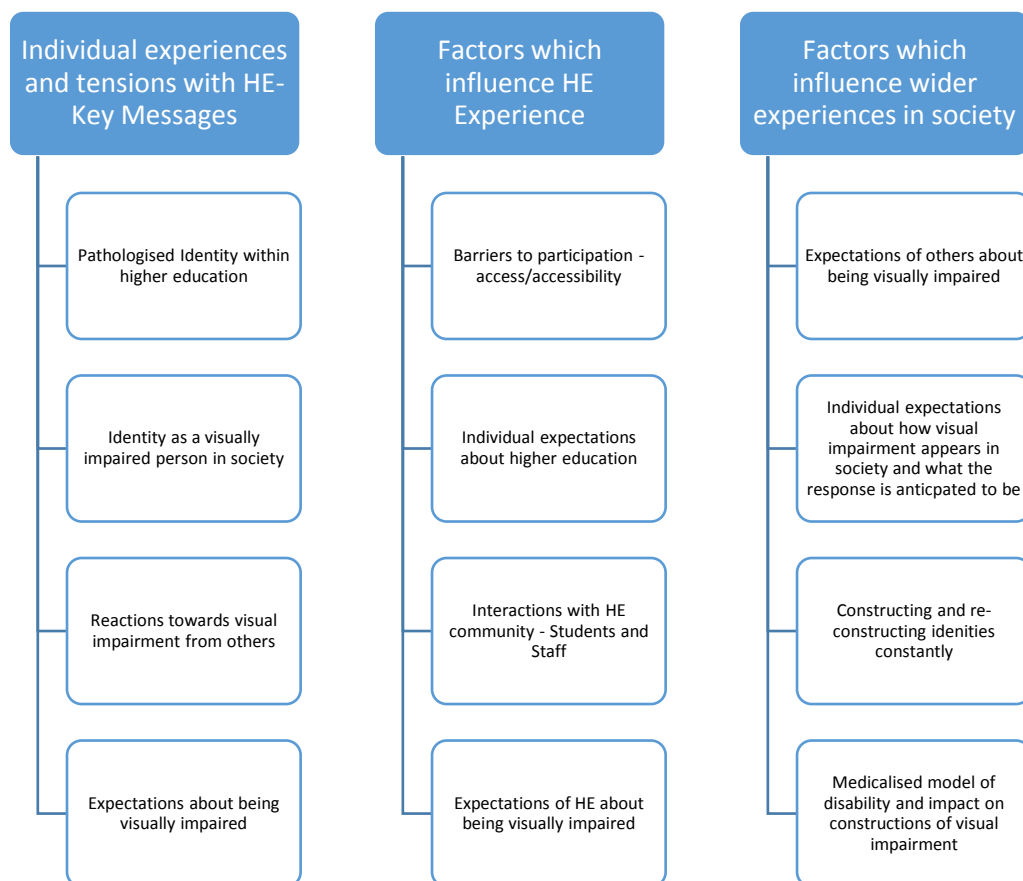
Please can you tell me how you feel you fit into a visually impaired/disabled world?

Tell me about how your view of this may have changed?

Do you feel like university changed this and how?

Do you feel that society is accepting of visual impairment and to what extent?

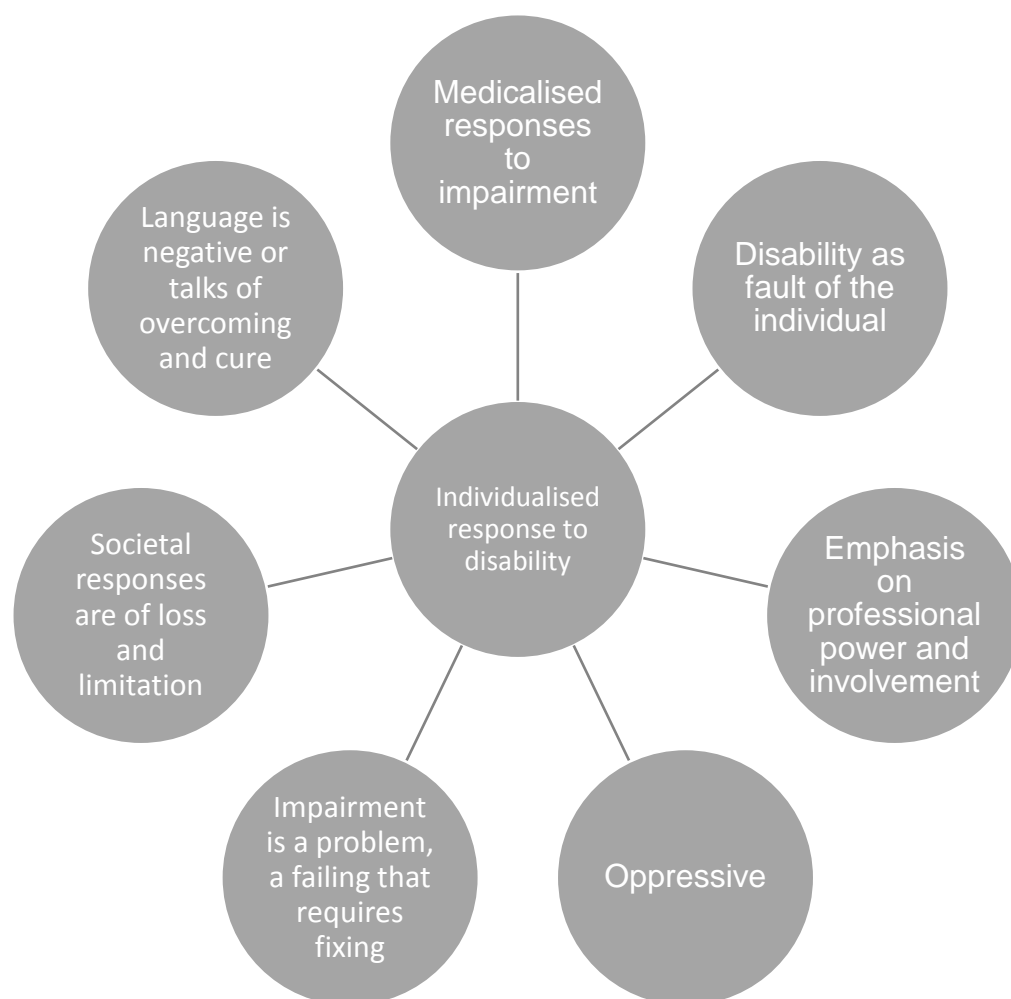
### Appendix Three: Diagram of Key Themes



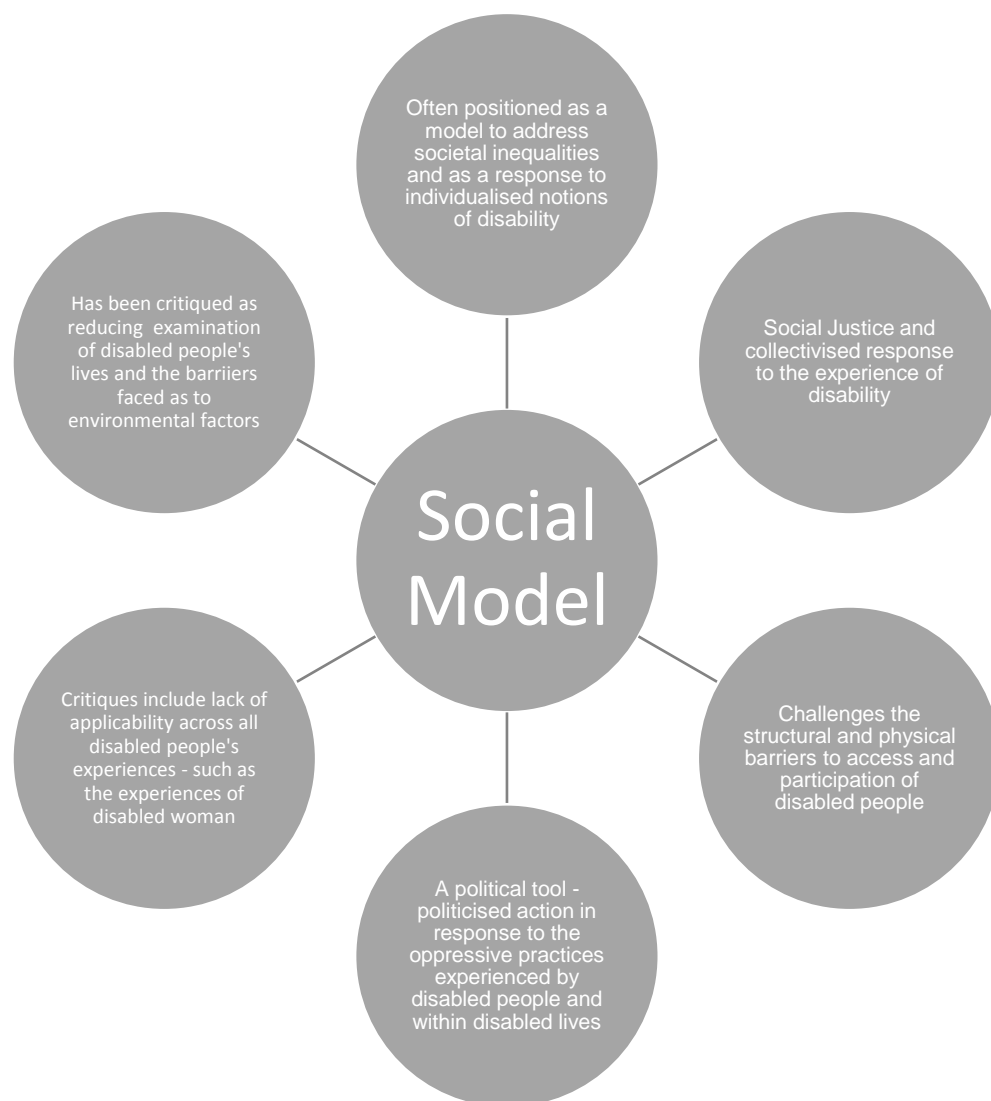


## **Appendix Four – Diagrams of Theoretical tensions**

### **4.1 Medicalised**



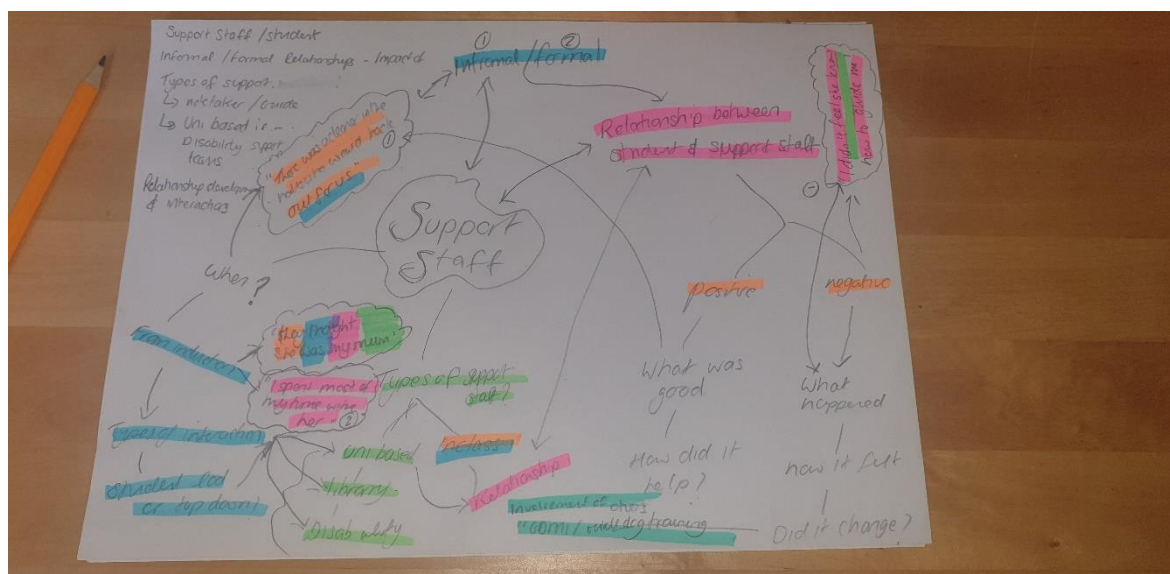
## 4.2 Theoretical Tensions



### 4.3 Theoretical tensions



## **Appendix Five: Example of thematic analysis**



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## **Abbreviations**

CDS – Critical Disability Studies

DS – Disability Services within the University

DDA --Disability Discrimination Act

DSA – Disabled Students Assessment/Allowance

FE – Further Education

HE – Higher Education

HEI – Higher Education Institution

OfS -- Office for Students

SSI – Severely Sight Impaired

VI – Visual Impairment or Visually Impaired