# Out of sight, out of mind: Accessibility for people with hidden disabilities in museums and heritage sites in Northern England.

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# Abstract.

As of 2020, an estimated 14.1 million residents of the United Kingdom reported a disability (DWP 2020). Within this population, approximately 6.1 million people have a hidden disability (Buhalis and Michopoulou 2011). These hidden disabilities range widely, from neurodiverse conditions like autism and dyslexia to long term chronic conditions such as fibromyalgia and arthritis. Due to the wide range of disabilities and their impact on a disabled person's life, they have generally been underrepresented in accessibility studies.

This thesis uncovers the accessibility needs of people with hidden disabilities, specifically in museums and heritage sites where they have heretofore mostly been overlooked. I utilise semi-structured interviews and correspondence with people with hidden disabilities, as well as participant-led experiences through three case study sites in Northern England, to understand the barriers they face. Their experiences help me expose the importance of passive accessibility – accessibility measures built directly into an exhibition design, such as adequate lighting and personal interpretation boards.

Additionally, this thesis aims to understand the cultural forces that prevent or support accessibility-related improvements to such sites from taking place. By studying the cultural make-up of each case study organisation through ethnographic observations of the staff at these sites, institutional roadblocks to enacting accessibility-related adjustments are revealed. Specifically, the lack of communication at these sites presents a significant barrier to enacting accessibility suggestions from disabled visitors.

Tying together the themes of active/passive accessibility and lack of communication is the theme of gaps in disability awareness, by which I mean that heritage organisations do not wilfully create these barriers to inclusion, and yet they create them still because they simply do not realise these things. Filling these gaps opens up countless possibilities for improving accessibility not only for people with hidden disabilities but for all visitors and staff at museums and heritage sites.

# Contents.

# List of Tables.

# List of Figures.

# Preface.

As a child, I always looked forward to our annual school trips to the Field Museum in Chicago. As a child with undiagnosed anxiety and OCD, I also found them... challenging.

I loved walking through the marble-filled main hall, marvelling at the massive dinosaur skeleton, taxidermized elephants, and imposing totem pole. I especially loved walking through the replica Egyptian pyramid, following the twisted corridors up and down the structure, finally emerging into an immersive recreating of Ancient Egypt, complete with a fake river that ran along one end of the exhibition hall. The Egyptian exhibit was filled with hands-on, interactive activities, something that was unheard of in the early 1990s. Children could run around the hall, pretending to draw water from the fake river or grind wheat with replica quern stones. They could marvel at precious artefacts safely encased behind glass whilst running their hands all over replicas sat right in front of them.

However, the combination of hard floors, stone walls, and wooden cabinets also meant that the exhibition hall was very, very loud. Any museum visitor who has encountered a school group will tell you how loud these groups can be, but as one of the school children, I spent every field trip feeling anxious, overwhelmed, and desperate to go home. My only respite was a tucked away corner of the Egyptian hall, with a faux mud brick alcove protecting the area on three sides. There were no interactive elements in this area, nothing to touch or play with, so most other children avoided the area. I, however, would happily spend days in that area. Not only because the faux mud brick walls held mummified animals and statues of the goddess Bastet that I could stare at for hours, but also because I could escape the overstimulation I experienced in the rest of the exhibit.

Little wonder, then, that 25 years on, I'm now working in museums and striving to find more tucked away corners to shelter visitors who need the respite. This thesis is my way of proving everyone can be included in heritage, and that no one needs to experience a bad field trip due to ableist barriers.

# Acknowledgements.

When I first suggested to Sara that I wanted to pursue a PhD, she very seriously warned me that the process would change me. Without a doubt, I have become a different person in the four years it has taken me to complete this research. There is no possible way I could have accomplished this alone.

First and foremost, thank you to my participants, especially those who have since become friends, for trusting me with your stories. You have challenged me and opened my mind to new ways of seeing the world, and I am forever grateful that you shared your experiences with me.

Second, I have to thank my thesis advisory panel – Dr Gill Chitty, Dr Heather Smith, and of course, Dr Sara Perry. The wisdom, insight, and grace you wonderful women have shown me over the years is astounding, and has pushed me as a writer, an academic, and a person. I hope I can be even a fraction as brilliant as each of you are.

To Harald and our beloved late Don, thank you for joining this project so late in the game, when personal circumstances meant I needed a little more help.

To my friends and family, the support you've given me has been incredible. I have never felt like I'm bothering you if I needed to rant or vent or sob, despite my mounting anxiety over, well, everything.

Finally, to my Diglets. You, more than anyone else, have listened to me prattle on about accessibility for years. Not only that, you've taken my rantings and put them into practice, to the point that you're teaching me things about accessibility now. I'm so very proud to be amongst your ranks.

# Declaration.

*I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as References.*

# Chapter 1 – Introduction.

It all starts with a simple comment.[1]

I'm telling my friend Renee about a trip I'm planning to a museum in a different city, and that I've spent the past hour searching their website for every last bit of information I can find to prepare myself.

"Oh man," Renee says. "You have it lucky – you have no **idea** the ridiculous level of planning I have to do, just to visit a museum in my own city." Renee is a professor of Art History in the midwestern United States, a published academic, and an artist herself. She also has Type 1 Diabetes. By this point, my interest in museum accessibility has taken root, and we have had long discussions about the impact of diabetes on her life.

Curious, I ask her what she means.

"Well, for starters, I have to make sure I have extra insulin," she begins. She spends the next half an hour explaining to me the excruciating level detail she has to plan, everything from what shoes to wear (Type 1 Diabetes is notoriously hard on feet (Bowling, Rashid and Boulton 2015)) to where the nearest hotel is in case she's too ill to travel home and has to stay the night to recover. And this is only for a trip to the other side of her own city.

She then tells me multiple stories where she has almost been kicked out of an art gallery for quickly and unobtrusively eating a chocolate bar to prevent a blood sugar crash, which could lead to her passing out. More than once, a particularly harsh docent has reminded her that there's no eating or drinking in a museum –

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[1] I begin this thesis with a "vignette" – a short narration based on real events, which I further define and discuss in Chapter 4.

as if she was an uneducated, unaware member of the public, and not a professor with a PhD in Art History.

Finally, she turns to me with a sigh. "I just wish more people understood how difficult it is for people with hidden disabilities. There's a lot more to accessibility than ramps and Braille guides."

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Renee's frustration over inadequate accessibility in museums and heritage sites is becoming an increasingly important issue, especially as the number of disabled people in the world continues to rise (World Health Organization 2011, 8). Heritage sites are now increasing their accessibility offers, providing everything from large print guides to specialised tours for people with specific disabilities, such as a BSL tour at the Tower of London (Historic Royal Palaces 2021). It is commonplace now to see a session or paper about accessibility at museum conferences, like at the Museums Association's Exhibitionists: Design Great Exhibitions conference (Kufeldt 2018) and sessions such as "Enabled Archaeology: Making Field and Museum Archaeology More Inclusive for Dis/Abled Staff, Volunteers, And Visitors" at CIfA's 2022 conference (Chartered Institute for Archaeologists 2021). There are even entire conferences dedicated to museum accessibility, like the Museums as Agents of Change: Diversity, Accessibility, and Inclusion conference in December 2017 (US Embassy 2017). The National Lottery Heritage Fund requires all applications to consider inclusion and accessibility as part of their funding process, and even provides guidance on how to make NLHF-funded projects more accessible (National Heritage Lottery Fund 2021).

However, despite these advances, Renee's comments still ring true for many disabled people. In 2018, 64% of disabled people believed that levels of access for them remained the same from the year before, with a further 17% believing accessibility had decreased (Euan's Guide 2019, 6). Additionally, only 38% of disabled people are able to find the accessibility information they need online (Cock et al. 2020, 9), a startlingly low number given that 70% of disabled people actively seek this information before visiting a museum or heritage site (2020, 7) and more than half change their plans if they cannot find enough information regarding the

accessibility of a site (2020, 13). If accessibility is becoming a more common topic amongst heritage practitioners, why are disabled people not seeing any positive change?

A great deal of this disparity comes from how disability is conceptualised, as this conceptualisation then informs how museums and heritage sites view accessibility. It is therefore necessary to discuss the various models of disability in order to understand these differing viewpoints.

## 1.1. Models of Disability.

The definition of "disability" in the general consciousness is a narrow one. Most people, when they consider disability, often think only of wheelchair users, people with sight loss, or the d/Deaf community[2] (Hidden Disabilities 2021a). The British census takes a slightly different meaning, considering anyone who has their daily life impacted either "a little" or "a lot" by a health problem or impairment as disabled (Office for National Statistics 2015). The Government's definition is a more inclusive conceptualisation, allowing for a wider range of conditions, such as chronic illnesses, mental health conditions, or a learning disability – disabilities that are often overlooked by the general population.

As can be seen by the difference between the census statistics and the general knowledge of disability, there are varying perceptions regarding what disability is. In Disability Studies itself, there are various ways of understanding and defining "disability" that have formed different modes or "models" of disability. The earliest model to be articulated was the medical model, which first emerged in the 1970s and was cemented in disability studies with the publication of the WHO's International Classification of Impairments, Disabilities, and Handicaps (1980). Abbreviated as the ICIDH, it marked the first international attempt to classify disability to describe "the consequences of disease" (Üstün et al. 2003, 565). The model views disability as "any restriction or lack (resulting from impairment) of ability to perform an activity in

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[2] This is the preferred term for the community. It indicates deaf people, who have severe hearing problems, are different from Deaf people, who have been deaf since before they learned to speak. Deaf people in turn consider sign language their first language, rather than the native spoken language of their wider society (Sign Health 2021).

the manner or within the range considered normal for a human being" (World Health Organization 1980, 28).

This is very in-line with how most nondisabled people view disability: the person with the disability is lacking something that would otherwise make them normal. It is this 'lack' that is intrinsic to the person. There is something that is missing or limiting the person, whether it is a lack of ability to climb a set of stairs or a restriction in how many stairs a person can climb before exhaustion sets in. In the definition itself, the disability is also contrasted against 'normal,' which again assumes that there is something lacking in the disabled person. Their disability is something that must be compensated for, traditionally using a technical or medical device, which is where this model takes its name. The burden of 'improvement' is still on the disabled person, who must somehow compensate for their disability in order to interact with the rest of the world. Examples of accessibility measures that stem from the medical model include prosthetic limbs, wheelchairs, and cochlear implants. They change the individual and allow them to be more 'normal' in the wider world. This framing of disability as a loss, as a restriction, also has profound impacts on how a disabled person is then viewed. As Cameron points out, "the terms loss, abnormality, restriction, or lack of ability are heavily laden with cultural meaning and indicate a perception of impairment and disability as characteristics of individual deficit or personal tragedy" (2014, 99). The medical model not only singles out a disabled person as abnormal, but also sets them up as a tragic figure for not reaching the heights of human normality.

Despite its shortcomings, the medical model does put forward an important concept: impairment. Impairment refers to the "abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level" (World Health Organization 1980, 14). Problematic wording aside, an impairment is the physical aspect of a disability. It is the eyes that cannot see, the brain that cannot process written text, the joints that are inflamed. In many cases, these impairments lead to disability, but not always. For example, I am short-sighted and have worn glasses or contact lenses for over 30 years. According to the medical model of disability, my inability to clearly see anything more than six inches from my face represents a "restriction or

lack (resulting from impairment) of ability to perform an activity" (World Health Organization 1980, 28) and therefore is a disability.

However, I do not consider my short-sightedness a disability – thanks to the social model of disability.

In opposition to the medical model sits this social model of disability, which presents disability as a restriction imposed by society, rather than inherent in the person. The Union of the Physically Impaired Against Segregation (UPIAS), a society of physically disabled people who began to organise in the 1970s, first theorised the social model and became its primary advocate. They define disability as "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" (UPIAS 1975, 20). My short-sightedness does not exclude me from mainstream social activities, hence why I do not consider it a disability.

The social model of disability shifts the source of disability off the person and onto society, a difference that can be at least partially explained by the fact that this definition has been written and shaped by disabled people themselves. It has been created by the people who have embodied knowledge of disability rather than medical professionals (Oliver 2013, 1024). Here they resist the idea the medical model puts forth, that their disability is something that makes them lesser and that it is their onus to change. Rather, disabled people see their 'disabilities' merely as impairments that society has changed into disadvantages. One of my participants, Jessica, spent almost all her education with undiagnosed neurodiversity, something I explain in greater detail in Chapter 5. Her dyslexia meant that Jessica found it difficult to read and write to the same standard as her peers. The social model says that Jessica is not disabled because of her dyslexia, but rather because society places Jessica in situations where she is inherently disadvantaged – that is, she is put into educational settings without any support. As Jessica herself said, in this setting, she thought "I was just stupid and just needed to work harder. And actually, that was not the case" (Appendix C 7.1). In other words, she once found herself burdened by the medical model wherein her "abnormality" was situated firmly within

Jessica herself. However, she has now come to situate her disability within the social model, and subsequently realised "it's not because I'm stupid, I have a disability and I need some extra tools for me to be able to read and excel in studying" (Appendix C 7.1).

It is this social model that has pushed through legislation (Barnes 2006, 13) and cultural changes, such as the Americans with Disabilities Act of 1990. By framing disability as a problem with society, it is society that must adapt to people with impairments. Initiatives like universal design and inclusive environments, as well as disability awareness programs (e.g., Enhance the UK or Disability Matters), are borne from this social model and encourage a world that is more open and inclusive of impairments, wanting wheelchairs and accessible toilets to be as common and everyday as prescription glasses.

However, the social model has numerous flaws. Most significantly is a complete disconnect between disability and impairment. As discussed earlier, this distinction between disability and impairment was an important part of the medical model. In the social model, there is no consideration of impairment at all. This seems a natural conclusion if society is wholly to blame for disability. If society is what needs to change, then there is nothing "wrong" with a disabled person. However, as many disabled people will attest, they do have, for example, an organ that does not function as it was intended. Someone with Type 1 diabetes has a pancreas that does not control insulin like it should, yet a strict social model interpretation would not see this as a disability. This distancing between disability and impairment is necessary on some level, as it challenges the idea that all disabled bodies need to be cured, but the two cannot be completely disengaged from each other. Appropriately for this research, Wendell (2001, 23) points out that "recognition of impairment is crucial to the inclusion of people with chronic illnesses in disability politics. Chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, depression, and/or other impairments that are hard to ignore."

There are also examples of disabilities being hypothesised as beneficial to humans in the past. Spikins' (2013; 2010) ground-breaking work on autism in prehistory suggests that it was autistic characteristics that helped individuals to survive and

adapt during the Palaeolithic. In this way, the social model of disability is accurate: it is society that makes these impairments productive or not. However, the social model fails to account for the practical, daily ramifications of living with these conditions. Someone with Type 1 diabetes will still need insulin, and no amount of social awareness will change that (Wendell 2001, 18). To ignore very real medical needs entirely is not only a shortcoming of the social model, but also a dangerous one. As Mulvaney writes, "the social approach to disability must acknowledge the legitimacy of medical activities while, at the same time, critiquing these activities where appropriate if it is to identify the full range of social barriers people with disabilities face" (2000, 594).

As a way of addressing these shortcomings, Swain and French (2000) put forward the affirmation model of disability. They stress that it is not an alternative to the social model, merely that it builds on its principles and further refines the ideas already set out (578). Most significantly, it soundly rejects the intrinsic idea that to be disabled is to be a tragic figure. As the authors (2000, 578) write:

> An affirmative model is being generated by disabled people through a rejection of the tragedy model, within which their experiences are denied, distorted or re-interpreted, and through building on the social model, within which disability has been redefined. The affirmative model directly challenges presumptions of personal tragedy and the determination of identity through the value-laden presumptions of nondisabled people. It signifies the rejection of presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality. Whereas the social model is generated by disabled people's experiences within a disabling society, the affirmative model is borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity. The social model sites 'the problem' within society: the affirmative model directly challenges the notion that 'the problem' lies within the individual or impairment.

The personal tragedy model, although not a fully developed model in its own right, is in the background of both the medical and social models. Whether the disability is inherent in the person or the society, there is an understanding that the disability represents a lack of something, that the disabled person wishes to be without whatever is causing their disability. Under the affirmation model, a person's disability is every bit a part of their identity as is their eye colour. It is something that simply

makes up who they are, having the potential for both advantages and disadvantages. It does not negate that there are difficulties that they face, but rather acknowledges that there are also benefits. Or, as Roshni, a blind woman from Glasgow, said in an interview, "I've yet to meet anybody who is a hundred percent happy with who they are... There's lots of things I'm not happy about. I'm not happy about the fact that I've got dry rot in the next room and the ceiling needs replacing. I think my visual impairment is on the same scale as that... life happens" (quoted in Cameron 2014, 5).

A pertinent critique of both the affirmation model and the wider social model is that they are dismissive of the very real negative impacts of a disability. As Grue points out in his critique, "if impairments do have negative aspects, however, then in order to maintain an overall positive impression, there must be compensations" (Grue 2015, 207). If someone is blind, then the offshoot (according to cultural mythology) is that their hearing is better than non-blind people. There can be no emphasis on their lack, only their benefits can be stressed. This often takes shape in the form of "supercrip" identity, most often seen in Para-athletic games such as the Paralympics, where a disabled person is framed as "superhuman" or even part-machine. This is a highly criticised narrative that has strong opposition in disability studies and the wider disabled culture (for example, Silva and Howe 2012; Howe 2011), but it has grown out of the affirmation model of disability by rejecting any negative impacts of a disability.

A newer and rapidly accepted model is the "human rights" model of disability. This particular model has grown out of the Convention on the Rights of Persons with Disabilities, which I will discuss in Chapter 2. Briefly, the document outlines the inherent rights of disabled people as well as providing tools to protect and promote these rights. This model, then, "focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics" (quoted in Degener 6). In other words, it centralises the person yet still acknowledges that they may have difficulties stemming from their disabilities. Their disability does not encompass their whole identity but it does affect how they move within the world. Degener, one of the authors of the CRPD, notes, "the human rights model of disability is more appropriate than the social model to encompass the

experience of impairment, which might not always be bad but certainly can be" (17). As mentioned above, this was a common critique of the social model, that by situating disability as a social construct, it ignored the physical, daily impacts of impairments and did not seek to address those impacts. Again, Degener (12-13) states:

> Whereas the social model of disability neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life and early death due to impairment, and dependency, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed.

As will be explained in later chapters, this much more exemplifies my participants' experience of disability, and indeed, is the disability model I use throughout this research. I position accessibility as the removal of barriers, in line with both the social and human rights models in that it is society that has made a particular heritage site inaccessible. However, I also affirm and recognise the very real medical issues and physical impairments that my participants with hidden disabilities experience. Each of my participants has one or more hidden disabilities, and as will be shown throughout this thesis, their experience of being disabled varies from day to day, as the physical symptoms of their disabilities are not always consistent. In this way, the social model of disability does not help them, as it would consider them disabled one day but non-disabled the next. The human rights model, however, does "not require a certain health status or a condition of functioning" (7) - referencing being able to participate in a potentially disabling society, but for my participants, also their identity as a disabled person.

The human rights model is not a full departure from the social model in the same way that the social model departs from the medical model, but the human rights model does offer the 'next step' of the social model. Degener (9) writes:

> Anti-discrimination law can only be seen as a partial solution to the problem. Even in a society without barriers and other forms of discrimination, people need social, economic and cultural rights. People need shelter, education, employment or cultural participation. This is true for all human beings, and thus for disabled persons.

However, because impairment often leads to needs for assistance, it is especially true that disabled persons need more than civil and political rights.

Her inclusion of "cultural participation" is particularly relevant to my research, which is about the accessibility of museums and heritage sites, and another reason why I have chosen to use the human rights model to understand disability. It is not enough to stop discrimination, barriers to participation must actively be dismantled for disabled people to be fully included in all aspects of society.

A significant strength of the human rights model of disability is that it moves beyond the discussion of disability to a discussion of how to ensure disabled people are full participants within society. Lawson and Beckett put it this way: "the nature of the human rights model is prescriptive, rather than descriptive, in that it answers the question 'what should we do? 'to advance social justice for disabled people" (365). I view my research as more than a theoretical investigation of accessibility; I began this research with an aim to *change* the case study organisations I worked with in some positive way. For me, this research has been an act of social justice on behalf of my participants - and on behalf of other people with hidden disabilities as well. The human rights model of disability gave me the framework within which I could understand my participants' experience of disability, and therefore how these sites can remove disabling barriers whilst also acknowledging their very real medical symptoms.

## 1.2. Hidden Disabilities.

Throughout this introduction, and indeed, throughout the rest of my research, I have referred to hidden disabilities. A "hidden disability" is a disability that is not immediately apparent to an outside observer (Disabled World 2021). This can include a wide range of disabilities and impairments, from dyslexia to diabetes, and can even include some varieties of vision, mobility, or hearing impairments. Further discussion of the hidden disabilities relevant to my research is provided in Chapter 5, but these disabilities are very often overlooked by most people, even within disability studies, as they are not obvious or do not require physical aids as often as more visible disabilities. Although they are less noticeable, they are far from rare, with nearly half the disabled population having a hidden disability, as seen in Table 1 below.

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Table 2. European accessibility market size (in thousands).

| Market segments (numbers given in thousands) | Total demand for accessibility per type |
| --- | --- |
| Mobility impaired | 16,067 |
| Visual impaired | 1911 |
| People with deafness/hard of hearing | 986 |
| Speech impaired | 246 |
| Mental/intellectual impaired | 4519 |
| People with hidden impairments | 20,185 |
| Total disability population incl. long-standing health problems (age: 16–64) | 46,593 |
| Elderly population (>65) | 80,903 |
| Total demand for accessibility | 127,496 |

*Table 1. Segmentation of disabled population (Table taken from Buhalis and Michopoulou 2011, 153).*

Along with its abundance, the societal limitations, as per the social model of disability, of a hidden disability are increasingly being recognised. For example, in January 2018, the British government proposed changes to their rules for acquiring a Blue Badge, a parking sticker that allows people to use a disabled parking space or follow a different set of parking regulations, to be more inclusive of hidden disabilities (Department for Transport 2018). The change has allowed people with such disabilities to have better job opportunities as well as more active social lives thanks to less limitations on their mobility.

In the heritage sector specifically, there are small steps being taken to be more inclusive towards all disabilities in heritage. The Science Museum Group, which runs large national museums around the country including the National Railway Museum in York, appointed Direct Access to audit the accessibility of all their sites and suggest improvements (Museums + Heritage Advisor 2021b). The Geevor Tin Mine, a UNESCO World Heritage Site in Cornwall, created an immersive virtual reality tour for disabled visitors who cannot access the physical mine tour (The Geevor Tin Mine 2021). At Beamish, an outdoor living history museum that recreates daily life from different decades of the 19th and 20th century, a Wheelchair Accessible Vehicle is on standby every day to transport wheelchair visitors around the expansive site (Beamish 2021).

However, these small steps are still fragmented throughout the country and far from common. There is still no larger project that seeks to understand the barriers that people with hidden disabilities face at museums. There is still no larger research agenda to examine the institutional attitudes that prevent accessibility-related change from happening. Training is still being offered only by single-disability groups into awareness, accessibility, and adaptation of single disabilities (e.g., Dementia Friends or Autism Awareness).

## 1.3. Research Design.

The primary goal of my research is to understand the accessibility needs of people with hidden disabilities. As mentioned in section 1 above, I position inaccessibility in terms of the social model – it is society that disables a person, or, more specifically, creates an inaccessible experience. Therefore, in order to understand their access needs, I must examine the barriers they are faced with when visiting museums and heritage sites.

In order to understand these barriers, I examine them from the position of a visitor with a hidden disability and from the position of the museum or heritage organisation which is hosting that visitor. Therefore, my primary research questions are as follows:

1. What are the accessibility needs of people with hidden disabilities in a museum context?
2. What barriers are preventing these needs from being met?
3. What barriers are preventing change from being enacted?

With the first question, I have aimed to understand the lived experience of a group of individuals who have hidden disabilities. Hereafter I refer to these individuals as 'participants' or by their names, as described in Chapter 5. With their embodied knowledge, they are the experts of their accessibility needs as dictated by their disability. I conduct interviews with these participants who identify as having hidden disabilities, specifically interested in the daily impact on their lives. In doing so, I seek to better understand the implications of their disabilities, connecting their

experiences with other participants and looking for larger patterns, explored in Chapters 7 and 9.

With the second question, I seek to understand the specific barriers that manifest for my participants at three case study sites, namely Abbey House Museum in Leeds, Barley Hall in York, and Treasurer's House in York, described in more detail in Chapter 5. To this end, I conduct site visits with my participants, encouraging them to share their unique experience with me. In analysing the larger patterns present across their varied experiences, I find a common theme related to the embeddedness of accessibility which prevented them from fully enjoying their visit, explored in Chapter 7.

With the third question, I aim to understand the "hidden" barriers that prevent changes to accessibility at the organisational level. I theorise that many suggested changes to accessibility would not require a great deal of cost or labour, and yet a hesitancy and reluctance to enact accessibility measures on the part of many heritage organisations is palpable. In order to understand this hesitancy and reluctance, I conducted ethnographic observations and interviews with staff at my case study sites. Again, in analysing the larger patterns present in my data, I find two common themes related to these institutional barriers which suggest that lack of communication and lack of knowledge about accessibility needs are responsible for these barriers, explored in Chapters 8 and 9.

I focus on three sites in Northern England partially due to their locality and proximity to where I was based for my research, but also because York and Leeds both have multiple museums, yet little heritage research focuses on these areas. Additionally, nearly 1 million people living in the Yorkshire and Humber region have a long-standing illness or disability that impacts their day-to-day activities, representing 18.8% of the overall population (Office for National Statistics 2011b), which is slightly higher than the national average of 17.6% (Office for National Statistics 2011a). This higher percentage, although it does not specify the types of disabilities, means that more people in this area have accessibility needs that are likewise not being studied.

## 1.4. Thesis Structure.

This thesis is structured in 11 chapters, starting with this introduction, outlining models of disability, aiming to explain hidden disabilities, and expounding on my research goals for this thesis. It seeks to provide a non-specialist reader with enough background knowledge in disability studies and its terminology to understand the rest of my research programme. This chapter also positions my research within disability studies, explaining my research goals and how I address each of these goals within the text.

The second and third chapters position my research within a wider, interdisciplinary context. The second chapter reviews the relevant policies and initiatives that affect the context in which my research takes place. It explores the impacts of legislation at the international, national, and local levels, as well as examining initiatives within archaeology and heritage that specifically aim to reach disabled people and bring them into the sector. The third chapter reviews the academic literature on accessibility in an interdisciplinary context. Literature from heritage studies, tourism studies, and disability studies is considered, as is how my research contributes to the field of heritage studies.

The fourth chapter explores the current trend of Equity, Diversity and Inclusion in the heritage sector and how this research fits within that framework. I examine previous diversity initiatives and comment upon their efficacy, then discuss how the current push for inclusion has a better chance of success than previous attempts.

The fifth chapter describes my methodological process, particularly my use of focused ethnography. I also explain the finer points of my data collection, divided between my participants with disabilities and my case study sites. I include a consideration of the ethics involved in conducting research with disabled people, informed by emancipatory research principles. I also discuss my own journey over the course of this research from nondisabled researcher to disabled researcher.

The sixth chapter summarises the data that I collected through interviews, observations, and site visits with my participants. I introduce my case study sites and

the organisations that run them, including the specific staff members I interviewed as part of my research. I then introduce each participant, using their own words to describe their experience of being disabled and its impact on their daily lives.

The seventh chapter considers the significant impact of the COVID-19 pandemic on my research. I summarise the events of the pandemic and its impact on my research as well as the larger heritage sector. I also consider the impact of the pandemic on the disabled population, particularly my participants. I then discuss how each of my case study sites adapted their visitor experience and consider how these adaptations changed the accessibility of their sites.

The eighth chapter represents the first thematic analysis chapter, exploring the theme of Active vs Passive Accessibility. Using narrative vignettes (described in more detail in Chapter 6) taken from my site visits with participants and my observations at case study sites, I explore the impact of add-on accessibility measures and the barriers that they create. I argue that accessibility should be embedded into the very design of an exhibition from its outset, creating a more inclusive experience for all visitors.

The ninth chapter explores the theme of Lack of Communication at my case study sites. Again, I utilise narrative vignettes to explore the difference in communication styles, arguing that a lack of communication, particularly between front of house staff and management staff, creates a significant hindrance to any change around accessibility.

The tenth chapter explores the concept of gaps in disability awareness. I re-examine the previous themes through this lens, then consider a specific, significant instance that exemplifies the interplay between these three themes. I also explore how gaps in disability awareness can be overcome.

The eleventh and final chapter serves as a reflective, reflexive place where I consider the implications of my research. I explore potential areas for future research, as well as the adaptation that was required for my research due to the COVID-19 pandemic. I also consider the place of my own research within wider

contexts, as well as the changes that have come about at my case study sites because of my research.

## 1.5. A Note on Language Use.

In addition to debates regarding the various models of disability, a great deal of publications and articles in disability studies discuss the role of language, particularly in regards to how disabled people should be addressed. The "person first" position, which addresses this population as "people with disabilities," emphasises the shared humanity of people above all else (e.g., Jensen et al. 2013). The "identity first" position, which addresses this population as "disabled people," counters that their experience of disability informs their entire personhood, that it is impossible to separate themselves from their disability, and an attempt to do so would be tantamount to dismissing their experience as a disabled person (e.g., Gernsbacher 2017; Sinclair 2013). "Identity first" language is the preferred terminology here in the UK, according to the government and informed by multiple disability advocacy groups (Disability Unit 2021), and I therefore use it throughout my thesis when referring to the disabled population at large.

However, as part of my interviews with participants, I asked them if they considered themselves disabled (Appendix C). All but one participant did, and I followed up by asking if they preferred the label "disabled person" or "person with a (hidden) disability." Some people had no preference, but amongst those that did, all preferred "person with a (hidden) disability." Out of deference to my participants' preference, I therefore use their preferred terminology when referring to that particular population.

# Chapter 2 – Policy Review.

In this chapter, I review the policy-oriented literature relevant to accessibility in heritage. In order to understand what research is currently being conducted and why, context about the legal framework this research sits in is necessary. In Europe and the UK especially, it has been shown that societal change can happen more quickly through legislation (O'Brien 2016, 454; Barnes 2012, 17; Vanhala 2011; Vanhala 2006; Gooding 1994), and therefore, I offer a brief look into the most impactful disability legislation and initiatives, beginning with international efforts.

## 2.1. International landscape.

On an international level, there are three policy-related initiatives that arguably have the most significant and widest reaching impacts on the lives of disabled people. As discussed below, the WHO's International Classification of Functioning, Disability, and Health (2001), the UN's Convention on the Rights of Persons with Disabilities (2007), and the EU's Accessibility Act (2018) have set the tone for current international legislation, as well as disability research worldwide.

### 2.1.1. International Classification of Functioning, Disability, and Health – WHO.

Far and away, the international report with the greatest impact on subsequent legislation and even views of disability itself is the International Classification of Functioning, Disability, and Health (shortened to ICF herein), published by the World Health Organisation in 2001. At its core, it is a "classification of human functioning and disability" (World Health Organization 2001). Not simply a listing of disabilities and impairments, the report aims to improve communication between people, particularly policy makers, health-care workers, and researchers, by establishing a science-based language to describe health and function (5). In creating this common language, it allows comparison "across countries, health care disciplines, services, and time" (5), arguably paving the way for more robust research and interventions. The ICF is not intended to serve as any kind of diagnostic tool or a debate on how to view impairments, or, as the WHO calls them, "functions" (3). It is simply a common dictionary that everyone, no matter their location, can use to communicate with each other about bodily function.

Early on in its life, the ICF was referred to as the ICIDH-2, signalling that it was the descendent of the International Classification of Impairments, Disabilities, and Handicaps, known as the ICIDH. Published in 1980 by the WHO, this was the organisation's first attempt to codify a medical understanding of impairments and disabilities. In the WHO's own words, it "is intended to offer a conceptual framework for information; the framework is relevant to the long-term consequences of disease, injuries, or disorders, and applicable both to personal health care, including early identification and prevention, and to the mitigation of environmental and societal barriers" (World Health Organization 1980, 2). From the very beginning, the WHO have acknowledged that there is a social aspect to disability, in that there are environmental and societal barriers to disabled people's inclusion, but one of the greatest critiques of the ICIDH has been its sole focus on the medical aspect of disablement (e.g., Bickenbach 2015; Koutsogeorgou et al. 2014; Bickenbach 2010; Üstün et al. 2003). The framework sets up processes to identify and track impairments, especially their severity and progression, but there is nothing to identify environmental factors. The ICIDH, in my opinion, represents the worst of the medical model of disability, where all the focus is on the disabled person and how their body is "abnormal."

In its newer iteration, the ICF has tried to address these critiques. The classification of disabilities is divided into 4 categories: body functions, body structures, activities and participation, and environmental factors. Half of the categories are centred around external factors rather than internal factors, giving researchers the common language to discuss these societal barriers. True, these aspects of the ICF have not been used to their fullest amongst researchers, as most research still focuses on internal factors (Cieza et al. 2019; Kurtaiş et al. 2011; Giannangelo et al. 2005; Dahl 2002) rather than external factors, but the framework is there, and it is a step in the right direction for more internationally collaborative research.

Despite this evolution from the ICIDH, the ICF is still criticised for its emphasis on the medical model of disability, although the ICF itself claims to be a combination of the social and the medical models – what they dub the "biopsychosocial model" (World Health Organization 2011, 20). David Pfeiffer, a disability studies expert who led the

charge for the revision of the ICIDH into the ICF and had input into the wording of the new ICF, points out that the ICF still heavily medicalises disability, even when it does not need to. As per Pfeiffer, "The medical model which underlies the ICIDH2 assumes an ontology with an objective, empirical reality. In this so-called reality there are numerous dichotomies: sick and healthy; disabled and not-disabled; normal and abnormal" (Pfeiffer 2000, 1082). He believes that, within the harsh either/or reality that the report creates, there is no room for nuance or subtlety in understanding disability, which in turn creates a dangerous precedent that can support such evils as eugenics (1082). Although this may seem alarmist, it is a valid interpretation, in my opinion, as the medical model can and has been used to support the idea of 'abnormality' (e.g., Baynton 2011; Areheart 2008; Shakespeare 1998). Pfeiffer suggests that in order to redress the flaws inherent in the ICF, a "philosophical revolution to change the dominant values of worldwide society" (2000, 1082) is needed. This goal is a lofty one, which perhaps sits outside the purview of a document like the ICF.

Additionally, it could be argued the ICF must necessarily treat disability from a medical perspective. The authors of the document, the World Health Organisation, are far more suited to a medical model of disability, looking at the 'abnormality' of a particular individual, as they represent a medical view of the world. The ICF, at least, provides a baseline for discussion, a sense of universality that, according to the WHO, is able to translate across cultures. In their reply to Pfeiffer, Üstün et al. (2003, 830) write:

> The move to the universal approach is one of the strengths of the [ICF] and, indeed, the reason it can, and should, be employed to monitor the impact of disability rights legislation and assess increases in the participation of people with disabilities around the world.

For Üstün et al., the significance of the ICF is how it supports disabled people around the world. In the WHO's own words, the point of the ICF is "to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities" (World Health Organization 2001, 5). Indeed, before the document was published, it underwent

rigorous "field trials" to ensure "cross-cultural and linguistic applicability of the model and classificatory structure and language" (Üstün et al. 2003, 566).

The same cannot be said for the social model of disability. If a person is disabled by their society, then this necessarily means that two people with the same level of impairments will have different experiences of disability if they exist in different societies – indeed, even within one society. Although the social model is preferred when looking for solutions to barriers or understandings of the lived experiences of a disabled person, the social model makes cross-national comparison impossible. Utilising the medical model is perhaps not the method that disability activists would prefer, but in order for multiple societies and countries to discuss issues surrounding disability and impairment, it is necessary.

There are also some disabilities that are caused by medical conditions which have nothing to do with society. Type 1 diabetes, for example, is caused by a malfunctioning pancreas, meaning that the body does not produce enough insulin to control blood glucose (NHS 2021n). No amount of accommodation from society can change the fact that a type 1 diabetic needs regular blood monitoring and injections of insulin to merely stay alive. There are social interventions, such as free or subsidised health care, that can increase the person's standard of living and overall well-being, but the person will always be dependent on insulin injections to simply stay alive. As Üstün et al. write, "it is also a mistake, and a tragic one, to ignore or deny the value and appropriateness of medical intervention" (2003, 829).

Regardless of its controversies, the ICF has gone on to help shape other significant policies and legislation. For my research, it is vital in understanding the complexity that is disablement. It is not a matter of social vs medical--both must be considered. There are barriers that museums and heritage sites can dismantle to make their sites more accessible to people with hidden disabilities, but there are certain things that are beyond their control. A visitor with epilepsy may suddenly have a seizure, triggered by something completely unrelated to the museum and therefore the museum could not have done anything to prevent it. In cases such as this, the best a museum can do is have a policy in place for how to react, and to train staff appropriately.

## 2.1.2. Convention on the Rights of Persons with Disabilities – UN.

The United Nations Convention on the Rights of Persons with Disabilities (abbreviated to CRPD) was published in 2006. It is a landmark declaration, not only to protect and promote the rights of disabled people, but also to outline what these rights specifically are. They include equal treatment and opportunity in all aspects of life, from education to employment to housing (United Nations 2006, 16-21). By explicitly stating and then expanding on these rights, the CRPD gives disability advocates, scholars, and organisations the tools to hold State Parties accountable (Harpur and Bales 2010, 3).

What sets the CRPD apart from its predecessors is its emphasis on social inclusion in various forms, as mentioned above, and the framework set out for monitoring the implementation of this policy. This represents a paradigm shift (e.g., Crock et al. 2017; Bartlett 2014; Harpur 2012; Stein 2011) regarding the inclusion of people with disabilities, relying more heavily on the human rights model of disability. As mentioned in Chapter 1, it is from this document that the human rights model of disability is most fully developed. The CRPD takes the view that society is the primary disabling factor and therefore that society must change, with governments leading the way. However, it also acknowledges that there are physical implications of a person's impairments which will also impact their every day life..

As with the ICF, there are numerous weaknesses in the CRPD. Of greatest distress amongst disability advocates is Article 12, which seems to abolish diminished capacity in courts of law due to mental illness (e.g., de Bhailis and Flynn 2017; Freeman et al. 2016; Wildeman 2013). The Article itself seeks to establish the assumption of equal recognition before the law (United Nations 2006, 10), but many advocates worry about the phrasing of the Article and its potential implications. As de Bhailis et al. explain (2017, 15), "Article 12 views disability-specific criminal provisions including the insanity defence and unfitness to plead as incompatible with the guarantee of universal legal provision." The assumption of equal recognition before the law necessarily means that disabled people cannot be discriminated against due to their disability – but likewise, they cannot use their disability to explain their actions and claim diminished capacity. Additionally, there is no political,

legislative, or financial pressure for States to enforce these measures, aside from the Committee on the Rights of Persons with Disabilities which offers observations on States-submitted reports (34-36). Despite these shortcomings, the CRPD offers a monumental shift in its provision of a framework for governments to draw up legislation and policies to protect the rights of disabled people (Crock et al. 2017; Bartlett 2014; Harpur 2012a; Harpur and Bales 2010; Stein 2011).

Importantly for my research, Article 30 states that (United Nations 2006):

> States Parties recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities... enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

Culture is one of many areas of social life that the CRPD covers, but it is significant that museums are specifically included in this convention. Too often, cultural heritage and disability are discussed in different political spheres with little overlap between them. By including heritage in this convention, it highlights the importance of heritage as a means of social inclusion for disabled people, and provides further impetus for museums and heritage sites to take their access provisions seriously.

### 2.1.3. European Accessibility Act – EU.

In November 2018, the European Union passed the European Accessibility Act (abbreviated EAA), which aims to standardise levels of accessibility on certain products throughout the EU. In its opening memorandum, the EAA explicitly states that it is the CRPD that brought this particular EAA into being to help EU member states enact the requirements of the CRPD (The European Commission 2015, 2). The EAA sets out basic levels of accessibility for many consumer products and services, including ATMs, smart phones, ticketing machines, and e-readers. This marks a significant step forward in removing international barriers for disabled people, as there is more harmony and consistency between countries for travellers, but also because it ensures less unintentional discrimination. For example, by making self-service ticketing machines more accessible, this means that more

disabled people will be able to use them, and therefore need to use ticketing counters less (Petrie and Darzentas 2018; Petrie et al. 2014). This may seem a small matter, but ticketing counters often involve queueing and face-to-face interaction, both of which require more time and effort on the part of the disabled traveller. Additionally, forcing this face-to-face interaction leaves them vulnerable to negative attitudes towards disabled people, an attitude which is startlingly common (see Chapter 3), and thus creates more strife, anxiety, and feelings of exclusion. Simply by ensuring that disabled people can use a ticketing machine like nondisabled people, all of these negatives can be avoided and the disabled person can have the same experience as any other member of society.

Naturally, the EAA has shortcomings. The European Disability Forum released a statement shortly after the provisional text was released expressing their disappointment and frustration (European Disability Forum 2018). Their main disappointment concerned what the EAA does not cover – namely, transportation services and infrastructure, buildings, household appliances, and microenterprises which, under the EAA, would be exempt as the Act would cause a "disproportionate burden" on their manufacturers (The European Commission 2015, 5). These are very understandable disappointments as they represent rather large holes in the legislative framework. Continuing the example from above, an accessible ticketing machine provides no guarantee that the service itself, be it train, plane, boat, or even event venue, is accessible for the ticket holder. Likewise, the exemption of microenterprises is worrying, as the EAA itself recognises that "most jobs in the Union are provided by SMEs [small and medium-sized enterprises] and microenterprises" (European Commission 2015, 4). If they constitute so large an employer and, presumably, so large a service provider, how can they remain exempt from these accessibility standards? Does their exemption not undermine the ambition of providing standards across the Union?

Thus far, it is difficult to determine the impact of the EAA on increasing inclusion for disabled people, as there are still future milestones for the legislation. The Act must be adopted into national legislation by the Member States by 28 June 2022, and the measures themselves must be applied from 28 June 2025 (Drabarz 2020, 87). Nevertheless, it represents one of the most ambitious pieces of multi-national

legislation to address accessibility, and it will be interesting to see how it is implemented in the future.

## 2.2. National landscape.

Beyond the international level, which aims at providing overall goals and standards, national policies and initiatives also impact on the day to day existence of disabled people. National legislation complements international regulations by adapting the international goals into actions that are most appropriate for the country. The CRPD, for example, sets out a framework for countries to create their own legislation, allowing for cultural nuances and tensions to be accommodated. Below I examine some of the more significant legislation and government programmes in the UK for disabled people, especially relating to museums and heritage. First is the Equality Act, arguably the most far-reaching policy, then I look at various British government initiatives, and finally the UK's Taking Part survey, which looks at the involvement of various minority groups in cultural programmes. I focus here only on the UK because it is the home of my three case study sites.

### 2.2.1. Equality Act.

Passed in 2010, the Equality Act codified a selection of "protected characteristics," including sexual orientation, race, and disability, and outlined prohibited conduct as well as non-discrimination actions that everyone in the UK (except Northern Ireland) is required to observe under the law. It was meant as a way to unify a variety of anti-discrimination laws, such as the Equal Pay Act (1970), the Race Relations Act (1976) and the Disability Discrimination Act (1995). In general, it protects people with these protected characteristics from discrimination, harassment, and victimisation.

In terms of non-discrimination, the Act covers a variety of areas including employment opportunities and treatment, access to education and housing, and engagement in political parties and other associations. Although it is only one of the nine protected characteristics, disability has its own special considerations. The concept of "reasonable adjustment" features heavily in these considerations, meaning that unlike the other protected characteristics, people with disabilities do not necessarily have a promise of strictly equal treatment. As has been shown across disability studies literature (e.g., Washington 2018; Fredman 2013; Sunstein 2007;

Light 2001), reasonable adjustment can be both a positive and a negative thing. On one hand, this "reasonable adjustment" acknowledges that barriers currently exist, such as stairs or text-heavy signs, and that some people are disabled by these barriers. The reasonable adjustments of ramps, lifts, and alternate accessible reading formats allow for people with various disabilities to access the same services and opportunities as nondisabled people. On the other hand, the phrase "reasonable adjustment" is incredibly vague and open to interpretation, leading many organisations to adopt a "good enough" attitude rather than adopting meaningful change within the structure of their organisation (Ineson and Morris 2006; Goodall et al. 2004). For example, Goodall et al. raise concerns that listed buildings will assume a separate entrance for disabled people is adequate instead of trying to make the main entrance accessible (355). Their concern, as it turns out, is valid, as in their accessibility audit of Speke Hall in Liverpool, Andani et al. (2013) describe this exact example. The main entrance to the Hall is inaccessible to many disabled visitors because it has a cobbled surface, stairs, and no handrail (24). Although there are alternate accessible entrances, "there are historic features on the main entrance which are unable to be fully appreciated by disabled visitors" (24). The "good enough" of alternative, accessible entrances means that disabled visitors to Speke Hall are denied the opportunity to experience and explore these historic features that nondisabled visitors can enjoy.

Nothing in the Act specifically mentions museums or heritage, although the "reasonable adjustment" provision obviously impacts these sites. This is perhaps not surprising, as the Act is meant to cover as wide a variety of services and organisations as possible, as well as a wide array of protected characteristics, and therefore it may be unreasonable to expect a direct statement on the inclusion of disabled people in heritage. As seen in Andani et al. (2013) as well as other research (e.g., May Lauder 2020; Coughlan and Lister 2018; Read et al. 2018), the Act has had an impact on accessibility across a number of sectors, including museums and heritage, giving disabled people a legal justification in "reasonable adjustment" to insist on equitable treatment and access.

## 2.2.2. Government Initiatives.

In an effort to provide resources for organisations to follow the provisions of the
Equality Act, the UK government has put forth a variety of tools and schemes. One
of the most significant schemes is Disability Confident Employers. As will be
examined later in Chapter 3, many people have a negative view of disabled people,
especially when it comes to employment. These attitudes are not necessarily born
out of hatred, but rather tend to be fuelled by inexperience and ignorance. It has
been shown that interaction with disabled people as well as training can change
mindsets (e.g., Schitko and Simpson 2012; Bizjak et al. 2011; Daruwalla and Darcy
2005): these are the driving forces behind the Disability Confident scheme.

The scheme provides guidance to employers on how to attract, recruit, and retain
disabled employees. Each Disability Confident resource developed for employers
begins with an overview of why employing disabled people can benefit an
organisation, working to break the negative idea that these employees would be a
drain on resources (Beyer and Robinson 2009; Louvet et al. 2009). The scheme's
documents include not only guidance for how to sign up to the scheme and progress
through the various tiers of confidence, but also case studies highlighting the
successes of the scheme and a listing of all the employers that have signed up to the
scheme. Like the Equality Act, this scheme encompasses all disabled people,
including those with hidden disabilities. In its guidance for employers, long-term
health conditions and mental health conditions are specifically mentioned and
clarified to count as disabilities within the context of the scheme (DWP 2018, 12-13),
a welcome change from most previous disability schemes.

Beyond employment, the UK government has also published a strategy policy to
guide the tourism sector in Britain through the next decade. One of the expressed
goals is "to make the UK the most accessible destination in Europe by 2025" (HM
Government 2019, 39). Interestingly, there is acknowledgement in the document that
the industry has already made great strides in increasing its accessibility offers and
that it is promotion and marketing that are now lacking, something that falls on the
shoulders of the British Tourist Authority, part of the Department for Culture, Media,
and Sport. Following this acknowledgement, the document identifies several steps

that the British Tourist Authority will take to remedy this oversight. These steps include incorporating accessibility into ongoing campaigns by highlighting accessibility offers, but also by including people with visible disabilities in their promotional material (40). Two of their three case studies specifically cite accessibility offers for people with hidden disabilities: Titanic Belfast discusses their partnership with AutismNI and their autism-friendly offers, like quiet spaces and ear defenders (41), and Wadworth Pubs cover their efforts in working to train their employees to be Dementia Friends – people who are specially trained in living with dementia and helping people with dementia (42). Unfortunately, like many other industries, COVID-19 has side-lined many of these plans, and currently, it is unlikely that the government will achieve their targets, as outlined in this strategy, by 2025.

### 2.2.3. Taking Part Survey.

Launched in 2005 by the Department for Digital, Culture, Media & Sport (DCMS), in partnership with Arts Council England, Historic England, and Sport England, the Taking Part survey monitors the engagement of adults aged 16 years and older as well as children aged 5-15 in a variety of "cultural, digital, and sporting" (HM Government 2021) areas. Although it only covers households in England, it provides statistics that allow for long-term analysis. Most significantly for this research, it monitors not just general population engagement with culture, digital and sport, but also the engagement levels of various minority groups, including adults with a long-standing illness or disability.

The most recent survey was published in September 2019 (although another was scheduled for publication in Autumn 2021 and delayed due to COVID-19), and features data on both heritage sites, and museums and galleries. Heritage sites, according to the survey, are categorised as "a city or town with historic character, a monument such as a castle, fort or ruin, and a historic park, garden or landscape open to the public" (Department for Digital, Culture, Media & Sport 2019, 7). There is no stated definition of "museum" or "gallery," but I understand it to be a specific building containing culture, such as historic objects or art pieces. The survey found that 69.9% of adults with a disability visited a heritage site during the period from April 2018 to March 2019 (16), while only 45.3% of adults with a disability visited a museum or gallery in that same period (13). These levels are lower than the general

population, which was 73.6% for heritage sites and 52.3% for museums and galleries. Across the board, all of these numbers have increased since the previous survey for 2017/2018, showing that more people in general are engaging with these places, a positive trend for the heritage and museum sector.

Although the survey itself provides no further synthesis, it does serve as the basis for a wide range of research. Everything from the participation of older people in the arts (e.g., Keaney and Oskala 2007) to the link between cultural exposure and social mobility (e.g., Scherger and Savage 2010) to regional disparities (e.g., Leguina and Miles 2017) has been explored using Taking Part survey data. Importantly for my research, Fancourt and Baxter 2020 explored the relationship between mental health and participation in community cultural activities (2020). Their analysis found that people experiencing low levels of happiness, as they would if they had depression, were less likely to participate in activities like visiting the cinema, attending an opera, or seeing an exhibition or art display (3).

## 2.3. Local landscape – Yorkshire.

As important as these nationwide disability-related initiatives are, it is on the local level that practical steps to address inequality and inaccessibility are often taken. Local councils manage social care benefits, such as blue badge applications and disability allowances, and therefore are most likely to interact directly with disabled people. Because of the importance of local council involvement, I now turn to examine the attitudes and policies of the cities that house my case study sites: York and Leeds.

### 2.3.1. York.

York is a city that is well known for its heritage and museums, consistently ranked as one of the best tourist destinations in the UK (Collier 2021; Dearskey 2021; Touropia 2021), especially for cultural heritage (Carr-Allinson 2021; Love Exploring 2020; Barratt 2018). The city welcomed 8.4 million visitors in 2018 (Make It York 2019), meaning that potentially over 1.7 million disabled visitors came to York in that year[3]. Most only come for day trips (Make It York 2019), but for residents of the city,

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[3] Based 20% of the UK population, per Scope 2021.

particularly disabled residents, living in York can be a challenge whether in or out of tourist season.

One of the major draws of York is its ambiance (Mordue 2007, 2005), thanks to its abundance of historical buildings within the city. However, it is this ambiance that often makes the city itself inaccessible to disabled residents (Yodan 2019). The Shambles, one of the most famous streets in York, is narrow, often crowded, and full of cobblestones and uneven pavement slabs. These aspects make for a charming photo opportunity, but they also make it impossible for a wheelchair user to traverse the street. Recognising this problem, the city itself has made improvements to be more accessible. The city centre, home to the vast majority of York's museums and heritage sites, has restricted vehicle access, making it easier for pedestrians (be they ambulatory, using mobility aids, or using wheelchairs or scooters) to get around. Blue Badge holders are exempt from these restrictions in order to drop off passengers closer to their destinations. Additionally, Blue Badge holders can park for free in the Council's car parks and on-street parking bays (City of York Council 2021).

However, during the COVID-19 pandemic, the Council came under fire for ignoring the needs of its disabled residents. In a bid to encourage and allow for social distancing, many more streets throughout the city centre were made pedestrian-only and Blue Badge parking spaces were removed (Johnson 2021). At the time, the Council said that the measures were temporary, even as disability activists in the city raised concern that they could not access the city centre with these restrictions in place. Indeed, these concerns came to fruition in the summer of 2021, when the Council proposed that these changes be made permanent. Again, disability activists were upset, but also not surprised. The lack of consultation with disabled people about these measures is something that disability activists have decried for a long time (York Disability Rights Forum 2021) and unfortunately, it seems as if York used the pandemic to accelerate previous plans that may have a drastic, negative impact on York's disabled residents. As Helen Jones of the York Disability Forum said, "when the pandemic hit, it felt like the council took advantage" (Johnson 2021).

## 2.3.2. Leeds.

Leeds, with its own storied history and heritage, does not have the same heritage tourism industry that York does. Although it attracts far more visitors – 30.42 million in 2019 (Visit Leeds 2020) – the largest industry in Leeds is its finance and business industry (Leeds City Council 2021b), suggesting that a significant portion of these visitors are work-related trips. Additionally, Leeds plays host to a number of significant sporting events each year (Visit Leeds 2021c) as well as a thriving theatre district (Visit Leeds 2021b) and numerous concert venues (Visit Leeds 2021a), which also add to these visitor statistics. Museums and heritage, then, are less visible on visitors' agendas. Indeed, only 1.7 million visitors in 2018 attended the nine museums run by Leeds City Council (Beecham 2019), a record number for Leeds yet only 5% of the total number of visitors to the city.

However, even if Leeds is not the cultural heritage destination that York is, the city still has a strong focus on improving the lives of its citizens, especially their disabled citizens. They have a specific equality and diversity section of their website (Leeds City Council 2021a), as well as an Equality Improvement Policy, and both the website and the Policy specifically mention disabled people. Additionally, they have published a Supplementary Planning Document called Accessible Leeds, which outlines the expectation of accessibility in planning applications within Leeds (Leeds City Council 2016). The document espouses a "pan-disability" attitude (4), meaning that they specifically mention hidden disabilities alongside other disabilities when discussing disabled people. The document also dedicates a section to Leeds historic environment, explaining that even listed buildings can and should be made accessible following the "constructive conservation" model (21-24), something I discuss in Chapter 3. They even use Leeds City Museum as a case study for effective adaptation of a listed building for increased accessibility without diminishing its historic importance or listed characterisation (23-24).

That is not to imply that Leeds is a perfectly accessible city, especially given its recent controversy over proposals to change a taxi rank location outside Leeds Railway Station to an area dubbed the "Dark Arches" that is seen as less safe (Norden 2021). But by enshrining the need for accessibility into their planning

process as well as highlighting equality and diversity as a priority on their website, they have shown their commitment to disabled citizens across Leeds.

## 2.4. Charity and tertiary sector.

In order to change societal attitudes, pressure must be applied from multiple angles. The government may be seen as one angle, but equally important is the work of various charities and non-government organisations. Groups such as the Union of the Physically Impaired Against Segregation have a long history of fighting for social change, both politically and within society itself (e.g., Baldwinson 2019). As will be shown below, the collective power of these groups has driven legislative change, and although the charities often amplify the voice of a specific disabled group, these changes can have an impact on a variety of other groups. Additionally, these groups have worked to incorporate disabled people in the practice of archaeology itself, changing attitudes and opening doors that might otherwise have remained closed.

As mentioned above, pressure from the political organisation of these charities and organisations has changed government policy. For example, because of a concerted effort by the National Autism Society, the criteria for Blue Badge eligibility have changed (National Autistic Society 2019; Department for Transport 2018). Blue Badge holders are able to park in specially allocated parking spaces, often nearest entrances, and also follow different on-street parking rules – for example, they can park on double yellow lines, which is normally prohibited. Before the proposed changes, there was a clear emphasis on physical disabilities, especially for wheelchair users, and people with other disabilities, such as autism or dementia, were excluded from the scheme. Under the new regulations, people who would encounter "very considerable difficulty whilst walking" from a vehicle to their destination would be eligible for a Blue Badge (Department for Transport 2018). This is a more inclusive requirement, as autistic people, people with dementia, and people with chronic pain would all experience different types of "difficulty" whilst travelling to their destination. By using their political sway, the NAS has made it far easier for many disabled people, including but not only autistic people, to get the support they need.

It is not just policy change that these charity and tertiary sector groups work for. Of relevance to my research, there are some organisations that actively work to introduce disabled people to heritage and archaeology. Perhaps most famously, Operation Nightingale provides wounded, injured, and sick military personnel opportunities to be involved in archaeological excavations (Wessex Archaeology 2021). During these excavations, service personnel are able to develop additional skills they can then use after they are discharged, as well as providing a safe place for them to work through the emotional and psychological difficulties that come with integration back into civilian life (Finnegan 2016, 17). There is ample evidence that these excavations have a hugely positive effect on the service people who take part in them, (e.g., Everill et al. 2020; Farrell-Banks 2018; Rush 2012), and at least one participant has gone on to become a professional archaeologist (Winterton 2014), proving how important programmes such as Operation Nightingale are in bring disabled people to archaeology.

Another organisation that is working to encourage disabled people into archaeology is the Enabled Archaeology Foundation (EAF). Begun in 2017 by the late Theresa O'Mahony, the goal of the EAF is to empower disabled people (not just military personnel, like Operation Nightingale) who want to enter field archaeology. Her passion comes from her own experiences as an undergraduate, applying to 38 field schools and subsequently being rejected by 36 of them based on her disability, as well as her own experience of discrimination within the sector (O'Mahony 2018, 216). As such, her work focused on accessibility for disabled field archaeologists, showing that simple, cost-effective measures can be taken to include wheelchair users, blind archaeologists, and even archaeologists with hidden disabilities such as dyslexia (O'Mahony 2015). However, as with many initiatives within the disability sphere, although hidden disabilities were included, they were a small segment of the research and even then, represented an even smaller section of people with hidden disabilities – in this case, people with dyslexia.

In September 2021, a new pilot programme was launched by York Archaeological Trust called Archaeology on Prescription (York Archaeology 2021). The first 9-week pilot brought field archaeologists and participants together to excavate a former care home within York's city walls. Participants are recommended to the project as part of

a social prescription initiative from partner organisations, including Converge, which works with adults who use mental health services (Converge 2021). Participants then take part in the excavation alongside field archaeologists, learning new skills and building confidence (York Archaeology 2021) as well as offering a new social network for participants. A particular aspect that sets this project apart is its focus on hidden disabilities. Although specific disabilities were not disclosed, all Converge participants have some kind of mental health condition, widely recognised as a hidden disability (Drake et al. 2012; Goodley 2001; Mulvany 2000). The fact that Archaeology on Prescription focuses on participants specifically with hidden disabilities is encouraging, and although the sustainability and impact of the project remains to be seen, it is a much-needed step towards the wider inclusion of disabled people in archaeology.

As my PhD came towards its end, another a new programme called Curating for Change was announced, which aims to provide "18-month fellowships to eight disabled people – and 40-day traineeships to another eight disabled people" within the museum sector (Pring 2021b). These eight fellows will look through collections and archives to "improve the way disability history is represented in museums," and the programme also aims to break down barriers that disabled people face when trying to enter the museum sector. Importantly to my research, the creators of the programmes consulted a variety of disabled people, including neurodivergent[4] people. Again, the inclusion of people with hidden disabilities in designing a fellowship such as Curating for Change is a welcome turn towards more inclusive action in the museum sector.

## 2.5. Summary.

In examining the legislative framework, government initiatives, and tertiary sector programmes and projects related to disability and accessibility, the context of disability research is more understandable. Progressive social legislation is informed by research, but likewise, research occurs in response to legislation, seeking to understand its impact and ramifications. In the next chapter, I examine the academic

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[4] "Neurodivergent" is the preferred term for people who have impairments that have traditionally been classified as learning disabilities, behavioural issues, or mental illnesses (such as autism, dyslexia, OCD, etc.), as it is now understood that their brains work differently than "neurotypical" brains.

research relevant to my research – research that has been informed by the policy
frameworks I have just discussed.

# Chapter 3 – Literature Review.

Having explored the legislative and policy groundwork relevant to accessibility on the international, national, local, and charity levels, I now turn to the academic research regarding accessibility. Some studies have been conducted on the topic of accessibility by researchers and professionals in the heritage industry, but much of it is fragmented and site-specific, making it difficult to apply to other museums and heritage sites. Due to this fragmentation, a wider frame of reference is necessary, exploring research across the tourism industry in an effort to form a more comprehensive understanding of current and past accessibility work in the cultural sector. Few studies have focused on hidden disabilities, making it necessary to review research that encompasses a variety of disabilities. In reading through the literature, three particular categories of scholarship become apparent. These include, (i) studies into the current status of accessibility, (ii) explorations of proposals to increase accessibility, and (iii) current and potential barriers to increased accessibility for disabled people. In this chapter, I consider each of these research strands and their relevance to my investigations.

## 3.1. Current State of Accessibility.

The access needs of disabled people are incredibly wide and varied, which is why research into this field will never be fully complete. Disabled people are not a homogeneous group (Blichfeldt and Nicolaisen 2011, 81), and even within a particular disability, there are a wide variety of needs (Figueiredo, Eusébio and Kastenholz 2012, 545) and levels of disablement (Buhalis and Michopoulou 2011, 157). There will always be room for improvement, and as the world's population ages, there will also be more need for accessibility services (McKercher and Darcy 2018; Pagán 2015; Buhalis and Michopoulou 2011; Darcy and Dickson 2009).

A basic starting point for research into accessibility is to audit current offers at museums and heritage sites. Many studies are simply this: reviews of what different sites in different places are doing or reflections on the state of affairs cross-institutionally. In Britain, such audit-oriented work is a particularly forceful branch of research that is often led by disability organisations. Euan's Guide, a website that

allows users to comment on public spaces' accessibility, and VocalEyes, a charity to support people who are blind or partially sighted, both run regular surveys into current accessibility at public venues. Euan's Guide produces a yearly survey regarding the importance of accessibility, answered by their website's users(Euan's Guide 2019; 2018; 2017). These surveys show that accessibility in most places is still deficient, and that a large percentage of people with disabilities avoid places altogether because of uncertainty about accessibility options (Euan's Guide 2017, 4; 2018, 11). VocalEyes publishes a bi-annual "State of Museum Access" survey that, initially, examined the presence of accessibility information on museum websites. Although it does not then verify the accuracy of any information on the websites themselves, it does show how little information there is on most museum websites (Cock 2016, 7). In their 2020 survey, they shifted their focus to the experience of disabled people who use these access services (Cock et al. 2020, 2). This survey found that disabled people wanted more access information available online, more accessible events, and better staff awareness (5). Combined with the results of the Euan's Guide surveys that show disabled people avoid sites that do not contain accessibility information, it is little wonder that disabled people are reluctant to visit museums.

Whilst these surveys are useful to see long-term change and are also critical in amplifying the voices of disabled people, they are not without their drawbacks. For instance, there is a notable lack of diversity amongst the disabled people surveyed. VocalEyes is a charity that works with and on behalf of blind and partially-sighted people, and as such, their research focuses primarily on this demographic of the disabled community. Euan's Guide, which was founded by a wheelchair user, has had a focus on physical accessibility, especially for wheelchair users, in previous surveys. In the latest versions of each survey, however, there have been comments from respondents regarding the increase of awareness of hidden disabilities, suggesting that the demographics for these surveys are widening. Indeed, in the 2020 VocalEyes survey, they partnered with Autism in Museums, an initiative to raise awareness of accessibility in museums, particularly for autistic visitors. Such a partnership led to noticeable changes in the survey questions themselves, as they were more inclusive of the experiences of other disabled people. Hopefully the trend

will continue, bringing more disabled voices into these surveys and providing more well-rounded and inclusive results.

Complementing such surveys and audits are comparable scholarly analyses, which tend to be more narrowly focused. For example, Mesquita and Carneiro (2016, 380) analysed the accessibility of 28 museums in four cities across Europe (London, Paris, Lisbon, and Madrid) to determine how accessible they were to visitors with visual impairments. They developed what they call a grid system, a set of specific, established accessibility measures (such font size on signs, tactile activities, and staff training), to facilitate their analysis (381-2). They found that there are wide discrepancies in implementation of these accessibility measures across the sites (385). Even at a specific museum, the building itself may rank highly on its accessibility but the exhibitions, both in design and interpretation, could rank very low (385). In practice, this means it may be easy to get into a museum, but difficult to understand or even experience the exhibitions. For example, 95% of museums did not have glass front doors, which are difficult for people with visual difficulties to see (382), but less than 20% of museums offered either tactile ground indicators or relief maps of the museum, both which help people with visual difficulties find their way around (383). It may be easier for these visitors to come in the front door, but little attention has been paid to helping them move around the museum itself. The suggestions Mesquita and Carneiro make to address such discrepancies are low cost and require minimal effort, such as offering hand-held magnifiers to help people better see signs and artefacts, showing that increasing accessibility need not mean dramatically increasing an exhibition's budget (384). However, their survey only examined accessibility measures that aid people with visual difficulties, which represents a small percentage (4.1% as per Buhalis and Michopoulou (2011)) of disabled people in the study areas that they focused upon.

In her 2015 research, Lapszynski reviews the digital technologies at three different American museums (The Metropolitan Museum of Art in New York, the Museum of Science in Boston, and Philadelphia's Magic Gardens) and how they may be used by disabled patrons. She found that all three sites have not fully realised the potential of these technologies. For example, she critiques the Met's use of audio guides, which are generally seen as an accessibility aid and yet do not have any primary

focus for disabled people who may use it as such (30). Most audio guides assume that a user can see a particular object or installation, as there is little to no descriptive narration of it. How can this be an accessibility aid if it still assumes a user has no sensory impairments, particularly visual impairments? Without this descriptive narration, someone who is unable to see the object, either because of visual impairments or height differences or a number of other reasons, still is excluded from the experience.

For their online offerings as well, the three museums are generally disappointing. Philadelphia's Magic Gardens primarily uses social media to curate their presence, something that Lapszynski praises as a means of strengthening bonds between the museum and its patrons and also providing room for a user to create their own unique narrative (2015, 45). However, this interaction does not necessarily focus on disabled people, and as McMillen and Alter point out, social media does little to include disabled people – unless they are specifically targeted – and can even actively exclude people with certain disabilities (2017, 7). The Met and the Museum of Science both offer a wide range of online materials, especially videos, podcasts, and mobile apps (Lapszynski 2015, 31-32 and 38-39) but they tend to exclude disabled people. The Museum of Science's online videos rely on a user being able to both see and hear what is being conveyed, something that automatically excludes people with visual or hearing difficulties (39). Likewise, the Met's online videos have no captioning nor do they provide audio description of any of the artworks which they are explaining (31). These are profound barriers that keep disabled people from being able to participate and learn from their websites.

Primarily, Lapszynski focuses on accessibility for visitors with mobility, visual, or hearing difficulties (2015, 29-30; 38-39; 43-44), although attention is also given to tactile exhibitions and aids which are helpful to not only these populations, but also people with sensory difficulties and neurodiverse people (38; 44). That being said, it is disappointing to read that Philadelphia's Magic Gardens, which already has significant physical access problems with no lift, escalators, and limited ramps (43), has begun the process of scaling back their tactile aspects in the name of conserving the fabric of the garden (44). This is not to say that accessibility should necessarily trump conservation, but there is no indication that any alternative will be put into

place to fill the gap that will be left behind when they take away these hands-on experiences. Overall, Lapszynski's research highlights how easy it is for museums to overlook disabled people in their adoption of digital technologies and thereby create one more inaccessible area of their museum, something that is corroborated by McMillen and Alter (2017), mentioned above, and Chancey Fleet's research into accessible technology (Access: Special Interest Group on Accessible Computing 2020; Fleet 2019). Fleet, a blind researcher, focuses on unintentionally exclusive coding within social media, something she dubs "encoded inhospitality" (Fleet 2019). According to Fleet, although technically accessibility options are present in social media, such as the option to include alt text on photos for screen readers, they are often buried within settings, putting an inordinate burden on the user to make their content accessible (Access: Special Interest Group on Accessible Computing 2020; Fleet, Choi and Guzman 2020).

Sometimes accessibility audits, such as Lapszynski's (2015), do not examine a site's entire offerings, but rather focus on a particular aspect of it. This is the case in Martins' research (2016), where she examines a sign-language tour given at Calouste Gulbenkian Museum in Lisbon, Portugal. The tour itself was organised by the Deaf Portuguese Association, who co-wrote the tour along with the museum's education officer, and not only discussed various objects in the museum, but also the role of d/Deaf people in cultures and time periods that were related to these objects (204-5). The crucial aspect of the tour was that it was delivered in sign language, the primary language for most of the visitors on the tour. According to Martins, this created a far more welcoming atmosphere than simply providing written transcripts, as most people who use sign language use it as their primary language, with the written word being a secondary language – in this case, Portuguese (203). Therefore, it is actually more difficult for them to understand the written language, which can bar them from fully engaging with the information that is being presented and makes the experience less accessible to the very people it is intended to help. This case study shows the importance of flexible thinking in accessibility, and that working with disability organisations can open doors to more creative and more inclusive efforts. Perhaps a sign language-led tour may not be optimal for every visitor who walks through the door, but as museums are increasingly offering information in other languages (e.g., Garibay and Yalowitz 2015; Huerta and Migus

2015; Martin and Jennings 2015; Marlow and Clough 2007), sign language should not be overlooked as an option for translation.

There are exceptions to this single disability focus, of course, one being a 2007 project based at the University of York on the accessibility of Canons Ashby, an Elizabethan Manor House in Northamptonshire (Bennet 2007). In her thorough examination of Canons Ashby, Bennet highlights various accessibility issues present at the site (2007, 21-34), although they do not limit themselves to one particular type of disability when examining these issues. Perhaps predictably, physical access is primarily discussed, particularly how a wheelchair user is prohibited from visiting a large portion of the site due the site's historic nature and lack of lifts (21-23). However, physical barriers as they apply to people with visual difficulties are also discussed, such as ill-placed chairs that partially obstruct doorways, uneven surfaces, and loose carpet edges, all of which present obstacles to visitors who may not be able to see these hazards (28-29). Likewise, Bennet also mentions how the audio guide, despite often being touted as a widely-available accessibility tool, is not particularly useful for visitors with visual difficulties, as it still assumes a level of visual ability (31). There is also an over-reliance on verbally-transmitted interpretation in the form of room stewards, which puts visitors with hearing difficulties at a disadvantage (31). As the author points out, no staff or volunteers at the site are trained in British Sign Language; likewise, not all hearing-impaired people can read lips, nor are the staff or volunteers trained in how to speak for lip-reading (31). By focusing on more than one disability, Bennet is able to examine and critique accessibility for a far wider population than most other academic surveys. Since the publishing of this thesis, it is unclear if any changes have taken place at Canons Ashby; however, their accessibility guide has greatly improved to include possible barriers such as surface types, number of stairs, and areas that are only accessible via stairs (National Trust 2021a).

While these multi-disability surveys seem to be the exception rather than the rule in heritage research, the same cannot be said for the wider tourism field. There are still single disability surveys, such as Power and Jürgensen's 2010 study of information presentation for people with visual difficulties, which outlines specific examples of accessibly-produced materials, such as audio guides (98), embossed paper (99),

and screen reader-compatible documents (101). There are far more examples of research that involves a wider array of disabilities or that affect a larger portion of the disabled population. Burns et al.'s 2009 study of disabled people's outdoor leisure experiences indicates that whilst most outdoor leisure providers believe that disabled people like to visit the outdoors in a rehabilitative capacity (409), most disabled people actually visit the outdoors for a host of other reasons including social inclusion, construction of identity, and personal wellbeing (410-2). Data were gathered from people with mental health difficulties, learning difficulties, visual impairments, and mobility issues (Burns et al. 2009, 408) to highlight the different barriers that disabled people may encounter in their enjoyment of outdoor leisure and how they can be linked to their disabilities. Likewise, Lehto et al. (2016) interviewed individuals with mobility, intellectual (learning), hearing, or visual disabilities to contrast the tourism experience of these individuals to that of their travelling companion (2). One of the things that they discovered was that whilst nondisabled people used tourism as a means of escaping the everyday (see also Ponsignon et al. 2021; Bodnar 2019; Smith and Kelly 2006), disabled tourists actually experienced a reinforcement of their everyday lives due to accessibility barriers at their destinations (Lehto et al. 2016, 4). Whilst analysing various complaints surrounding the inaccessibility of accessible hotel rooms, Wazzan (2015) used data provided by hotel guests with multiple types of disabilities. Although these disabilities were not disclosed, the types of access issues explored by Wazzan implied wheelchair users, blind or visually impaired guests, and guests with chronic conditions such as arthritis. They found that most accessible rooms were not designed with functionality in mind, like roll-in showers where a seated person cannot reach either the shower head or the taps to control it, thereby rendering the room inaccessible (Wazzan 2015, 5410), a rather ironic and frustrating outcome that emphasises the difficulty of disabled travel. By including people with a wide variety of disabilities, these surveys show how similar are the barriers that people with disabilities face.

This point about uniformities in experiences is articulated more clearly in a more recent multi-disability survey. McKercher and Darcy (2018) present a multi-tiered system of disablement which offers disability scholars and service providers a more systematic way to look at accessibility. They argue that the barriers which prevent

disabled people from travelling are not fully homogeneous, but there are
commonalities between them. These barriers can be divided into different tiers (see
also Figure 1):

- Tier 1: those common to all people (such as financial considerations).
- Tier 2: those common to all people with disabilities (such as ignorant attitudes from nondisabled people).
- Tier 3: those common to all people with a specific type of disability (such as a lack of accessibly-formatted information, i.e. Braille or large print guides).
- Tier 4: those unique to each impairment (such as a location to charge a piece of medical equipment). (60)
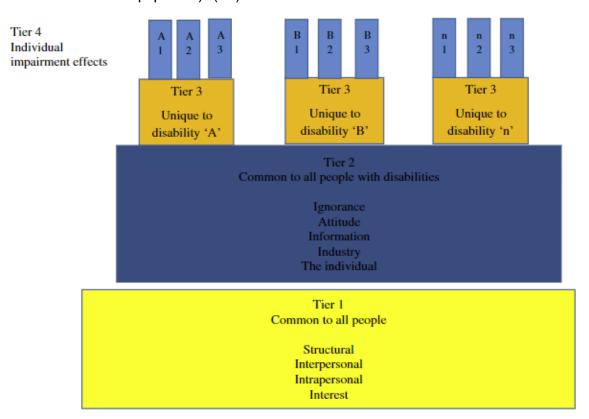


**Fig. 1.** Hierarchy of barriers to travel by people with disabilities.

*Figure 1. Taken from McKercher and Darcy 2018, 60.*

In discussion of these different tiers and how they affect a potential traveller,
McKercher and Darcy (2018) expound upon what Tier 3 barriers may be for different
types of disabilities. These include people with physical or mobility difficulties, people
with a visual disability, people with hearing difficulties, and, importantly, intellectually
or physically disabled children, which can be read as children with a learning

disability or who are neurodivergent (63). Although "intellectually or physically disabled children" still does not encompass as many people as it could (i.e., where do the access needs of a neurodivergent child and a neurodivergent adult diverge? Why could not both be considered?), it does acknowledge and explain that these kinds of hidden disabilities impact a traveller's experience and even desire to travel in the first place.

McKercher and Darcy's research in particular informs a great deal of my research. I use their tier system in Chapter 8 to explain how proposed changes to my case study sites, based on input from my participants, would benefit a wide number of people, disabled and nondisabled alike. Research of this kind, encompassing a wide variety of disabilities and accessibility needs, is critical to understanding how to improve a site and society more widely to be more inclusive. Multi-disability surveys highlight the differences in disabled people's experiences, but more importantly, they highlight the similarities. These similarities are borne out in my own research: people with different disabilities still encounter the same obstacles and can benefit from similar adjustments.

## 3.2. Proposals to Increase Accessibility.

But what could those adjustments include? Once a baseline of current accessibility offers is laid out, it is important to understand how to better accessibility at these sites. That is the question that underpins another line of related scholarship. In tourism research, studies on increasing accessibility can cover a multitude of different types of settings, from airlines (e.g., Chang and Chen 2011) to hotels (e.g., Tutuncu 2017) to different kinds of tourist attractions (e.g., Swaine et al. 2014). For example, Wan's (2013) study of accessibility in Taiwan's casinos offers several useful solutions that could be implemented at different types of tourist sites, as will be discussed below. However, her interviews were only conducted with people who are blind or who use a wheelchair or crutches (666). Although some of her suggestions, such as better staff disability awareness training (677), would benefit people with other disabilities, some suggestions, such as Braille buttons for slot machines (670), primarily or only benefit people with visual difficulties. This is not to imply that her findings are unimportant, but rather that studies that focus on only one

or two disabilities have limited potential for wider impact. Turning specifically to museums and heritage, there are several studies that lay out guidelines for improving accessibility for various disabilities. Kids in Museums, a group that provides advice and resources for museums to become more family-friendly, has put together two downloadable information packs to help museums become more accessible to different types of disabilities within families. One, which is for families with wheelchair users, includes practical steps for adjusting a current museum exhibition for better access. Some of these steps include spacing and heights of display cabinets, placement and text for signage, even pricing suggestions (Kids in Museums 2011, 2-3). The other, which is for autistic children, provides similar advice, such as providing visual stories so a visitor can familiarise themselves with the museum before visiting, assembling sensory backpacks for loans, even ideas for how to help limit sensory input that visitors with autism may find overwhelming (Kids in Museums 2018, 1-2). There is evidence that pre-visit materials, such as visual stories and floor maps of the museum, in particular help prepare autistic visitors (Langa et al. 2013, 328), proving the efficacy of these measures.

Both these resources also emphasise talking to people with these disabilities for more ideas, as well as disability awareness training for staff and volunteers (Kids in Museums 2018 3; 2011 1). These are two common themes throughout most research into accessibility: talking to disabled people directly for their input and training staff in disability awareness (e.g., Mullins and Preyde 2013; Figueiredo et al. 2012; Blichfeldt and Nicolaisen 2011; Burns et al. 2009; Shaw and Coles 2004). They are also two simple steps that apply to all disability types, as there is no disability that would not benefit from both. With training especially, one particular study with hospitality students showed that disability training, no matter the focus, increased positive attitudes towards disabled guests (Bizjak et al. 2011). I will return to this topic below, in section 3.3.2.

There are other examples of museums publishing guidelines and toolkits to increase awareness and accessibility across the industry. In addition to the Kids in Museums resource, Lurio (2016, 185) published a paper specifically for helping historic houses be more welcoming to autistic visitors, citing the unique nature of historic houses (although they do not clarify what they mean by this "unique nature"), in contrast to

more traditional museums, as a potential for better engagement with this population. Others, such as Langa et al. (2013) and Kulik and Fletcher (2016), surveyed families of autistic children to understand their motivations for engaging with museums and heritage as a way to better reach these audiences. Langa et al. found that families with autistic children visited museums as a way to experience something together as a family and also to "encourage the child's independence in exploring and experiencing" (2013, 329), although they also found that unpredictable stimuli were a barrier for many families, as they could not effectively prepare both themselves and their autistic children for these experiences (2013). Kulik and Fletcher found that whilst parents of autistic children appreciated autism-centric events, as it provided them with a sense of community with other families with autistic children, they were still frustrated and disappointed by the "stares and judgements they received from museum visitors and employees" during general operating hours (2016, 29). There are also examples of developing museum programming for D/deaf and hard of hearing audiences (Arts Council of Wales 2010) and visitors with dementia (Camic et al. 2017; Page et al. 2015; Rhoads 2009). For people with dementia especially, studies have shown that interaction in these museum-based programs provides them with social and physical stimulation, leading to increased mental health and overall well-being (Basting 2006; Cohen-Mansfield 2005; Silverman 2003). Again, autism and dementia feature very prominently as hidden disabilities that museums are keen to engage with, although little attention has been paid to other hidden disabilities such as dyslexia and chronic pain.

It is unclear why autism and dementia figure so heavily in the literature, but I would contend that it has to do with a subtle form of ableism. Autism and dementia are commonly seen as affecting children and the elderly respectively (World Health Organization 2021a; O'Connor and McFadden 2012), although both can affect people of any age. These populations are somewhat distanced from adults, who, in an ableist mindset, are meant to be nondisabled and require no additional help (Robey et al. 2006). Adults with visible disabilities are still very often discriminated against, from employment opportunities to housing and are even the victims of higher rates of violence (Mueller et al. 2019; Vornholt et al. 2018; Verhaeghe et al. 2016). Because of this, adults with hidden disabilities are often pressured to hide any special treatment they may need because of unwelcome scrutiny and policing by the

nondisabled population. Countless stories of adults being challenged for their use of blue badges and accessible toilets show in the news regularly, as well as multiple campaigns from various organisations to remind people that "not all disabilities are visible" (e.g., Crohn's & Colitis UK 2021; O'Malley 2019). Yet there is still a sense of shame amongst many who have a hidden disability, one that makes them acquire coping mechanisms to help them "pass" as nondisabled (Menendez 2018; Carey 2013; Cox 2013; Watson 2002). Even amongst other disabled people, those with hidden disabilities – especially chronic illnesses – are kept to the outskirts of the disabled community by those with visible disabilities. Even worse, people with hidden disabilities are sometimes outright denied "disabled" status, as they can "pass" as nondisabled (Griffiths 2020; Wendell 2001).

Although research into accessibility for visibly disabled people has taken great strides, research into accessibility for people with hidden disabilities is still woefully inadequate: few have been asked what sites can do to better accommodate them.

## 3.3. Current and Potential Barriers.

In light of the gaps, it is imperative to consider the barriers that prevent changes from taking place around increasing accessibility. Although each situation and accessibility measure has its own particular challenges, three factors in particular emerge when examining the literature regarding the difficulty in implementing improved accessibility: cost, attitudinal barriers, and conservation concerns. I discuss each in turn below.

### 3.3.1. Cost.

An oft-cited reason for resistance to increasing accessibility is a lack of funds (Lynch and Proverbs 2020; Persson et al. 2015; Andani et al. 2013). Certainly, budgetary constraints are a valid concern, especially in an era of endless austerity, but this excuse is based on a false assumption; i.e., all accessibility measures are expensive. The installation of lifts and ramps is assuredly an expensive undertaking, but as has been shown throughout this chapter, those are not the only means of increasing a site's accessibility. So why is there such a disconnect between what managers believe accessibility entails and what disabled people actually need?

Research into this disconnect has shown one particular trend: managers simply have little contact with disabled people, and therefore have an inaccurate view of their needs. For example, Capitaine (2016) interviewed upper level hotel management and found that most of their interviewees, who were placed at levels which dictate hotel policy, had no concept of what an accessible hotel room would look like. They found that some respondents believed (Capitaine 2016, 201):

- their hotels were accessible when a simple access audit found they were not;
- disabled guests were often accompanied by a helper, which would inherently compensate for non-accessible rooms;
- accessibility amenities were too difficult and "the boundary between adapted accommodation and hospital rooms was relatively difficult to establish".

Even more worryingly, "establishments with the accent on outdoor activities did not necessarily see the interest in developing accessibility, saying this clientele was less able to participate in such activities" (Capitaine 2016, 201). Not only do these respondents show a shocking level of ignorance regarding the needs of disabled guests, they can even display dismissive, discriminatory attitudes that further alienate potential guests. Recall Burns et al.'s research, which showed a great disparity between outdoor leisure providers' expectations of disabled visitors and the reality: most leisure providers assumed disabled people visited for rehabilitation purposes, whilst in reality, disabled people visited the outdoors for a wide array of reasons (2009). The inaccurate assumptions of these service providers regarding the needs of their disabled visitors lead to a dismissal of accessibility-related changes in the name of budgetary constraints.

In an attempt to bridge divide service providers and disabled guests, Kim et al. (2012) surveyed disabled hotel guests to determine their experiences and needs, then interviewed hotel managers to see how feasible it would be to improve their facilities. Many of the suggestions put forward were met with positive responses from hotel managers, such as changing key cards to have a corner cut (2012, 1316). This small change allows people with low or no vision to know which way a card must be inserted to unlock a door, but also is useful for people with no visual impairment to recognise the right direction more easily for a key card, especially in low-light

situations such as at night. Changing the key card shape, a move which has improved the experience of all hotel visitors, is a far cry from the "hospital rooms" that respondents in Capitaine worried they had to provide.

Additionally, as Lynch and Proverbs (2015) argue, many accessible improvements can be made without large budgets. In their research, they examined the implementation strategies of accessibility measures at Knole House, a National Trust property in Kent. They noted that several of these accessibility measures were of negligible cost (2015, 10), such as the inclusion of photographs on signs. As previously mentioned, Mesquita and Carneiro (2016, 384) likewise put forth inexpensive solutions for accessibility problems, such as handheld magnifiers. Many of the suggestions from Kids in Museums as well are inexpensive, such as visual stories and maps (2011; 1-2).

Although financial investments are a reasonable consideration for any organisation, these surveys make it difficult to believe that cries of "budget!" are based in reality. Instead, they appear to be based on inaccurate assumptions on the part of upper level management in these organisations that are themselves influenced by ableist (and therefore discriminatory) attitudes.

### 3.3.2. Attitudinal Barriers.

Staff attitudes greatly influence the overall impression of a visitor's experience, especially disabled visitors (Su and Teng 2018; Pop and Borza 2015; Navarro et al. 2014; Kim et al. 2012; Mey and Mohamed 2010). More often than not, they have a negative impact, as disabled people are often the victims of ableist attitudes. The idea that disabled people would not want to stay at a hotel with an emphasis on outdoor activities, as mentioned in Capitaine (2016), is an example of an ableist attitude. It presupposes a variety of things: that all disabled people have a physical or mobility-related impairment that prohibits their movement to a great extent; that disabled people have no desire to participate in the outdoors because of these impairments; that the only way to interact with the outdoors is through highly physical activities; that disabled people are only coming to these hotels to engage with their outdoor activity programmes as opposed to other offerings. All of these can be – and most, in fact, have been – discounted as false beliefs through a variety of research

(e.g., Burns and Graefe 2018; Burns et al. 2009; Shores et al. 2007), and yet the mindset remains even today. The impact of ableist attitudes cannot be discounted or underestimated, as they are as much a hindrance as any physical barrier someone may encounter.

These discriminatory mindsets are well documented in a variety of tourism-related roles, such as:

- travel agents (McKercher et al. 2003);
- hotel managers (Capitaine 2016; Paez and Arendt 2014);
- front of house staff (Bizjak et al. 2011; Bi et al. 2007; Card et al. 2006);
- other tourists (Tchetchik et al. 2018).

Although the attitudes of other tourists may be a delicate issue to address, it is imperative that the attitudes of service providers change. The negative experience of poor attitudes is a recurring theme amongst much of the literature (Su and Teng 2018; Mey and Mohamed 2010; Pop and Borza 2015; Navarro et al. 2014; Kadir and Jamaludin 2013; Kim et al. 2012; Goodall et al. 2004), but it is something that is easily corrected. Several studies have shown the impact of simple disability awareness training and increased contact with disabled people, all positive improvements. Bizjak et al. (2011), for example, ran two focus groups with hospitality students. One group was given a lecture about the social and personal dimensions of disability, while the other group was given a lecture about the economic impact of disabled visitors in the hospitality sector (2010, 848). Both groups were given questionnaires before and after these lectures to measure attitudes towards disabled people, and both groups were shown to have significantly better attitudes towards disabled people after the lectures (2010, 854). Interestingly, there was no statistically significant difference between the attitudinal improvement between the groups, which led the researchers to posit that it did not entirely matter which aspect of disability the students were exposed to: simply introducing them to these issues was enough to produce positive results.

Schitko and Simpson (2012) conducted a similar study on hospitality students, introducing an assignment about hotel accessibility to a number of students. At the

beginning and end of the term, all students were given surveys that, amongst other things, measured their attitudes towards disabled guests (2012, 328). They found that the inclusion of this assignment "softened" attitudes towards disabled people (2012, 333) and, more interestingly, this change lasted beyond the scholastic term. A year later, the researchers followed up with the students that had been given the assignment, and found they were able to recall information they had learned and their attitudes were still more positive than before they had been given the assignment (2012, 336). This suggests that even a small amount of exposure to disability issues is enough to heighten awareness and increase positive attitudes, an adjustment that can take place on many levels, either through formal education or as part of employer-based training.

Daruwalla and Darcy (2005) conducted another study involving two groups: one of college and university students studying tourism and hospitality, and another of tourism industry professionals who were attending a disability awareness training session as part of a government mandate (555-6). Attitudes were measured prior to training and after the training, once immediately after the training and another follow-up interview one month later. Again, any kind of training was shown to improve attitudes towards disabled tourists, but controlled interaction with a disabled person was most efficacious in creating long-term positive change (2005, 557). Likewise, at the follow-up interview, societal attitudes remained overall positive, although some personal attitudes had returned to pre-training levels (561). According to Daruwalla and Darcy, this difference between societal and personal attitudes suggests that consistent, ongoing interaction with disabled people maintains the overall positive attitude, as well as refresher training courses (562-3).

Once again, it is not difficult to overcome this particular barrier to accessibility. Despite how wide-spread and impactful ableist attitudes are, it is fairly easy to challenge and change these attitudes, via training and exposure to disabled people, to create more welcoming, accessible environments.

### 3.3.3. Conservation.

Another potential hindrance people often cite in increasing accessibility is the concern of conservation, specifically the alteration of historical fabric. This is

particularly relevant in heritage, where sites themselves may be situated in listed or scheduled locations and therefore have a certain degree of protection afforded to them. Any change to their physical character must be carefully considered (Historic England 2016), and often, it is assumed by building owners that it is paramount to maintain the historical authenticity of a site.

But is this actually the case? According to several disability experts, there is a tension and an inevitable compromise between accessibility and conservation. Pearne, for instance, puts forth a vexed argument that "facilities for disabled access, by definition, are symbols of modernity" and therefore must be managed carefully so as not to take away from the authenticity of a site (2011, 202). He cites the case of Lanhydrock, a National Trust property in Cornwall that installed a lift in the 18th century house. When the lift is not in use, it is hidden behind original oak panelling, "successfully disguising the 'modern intruder'" (203). However, he then goes on to argue that "disabled visitors have the potential for being… distractions through their conspicuousness, caused by their disability" (205) – a striking statement, given that it is within a volume about the importance and necessity of accessible tourism. Is he asserting that the mere presence of disabled visitors (visibly disabled, at least) takes away from the 'historicity' of a heritage experience, as if disability did not exist in the past? Clearly, this is inaccurate, as disability or at least impairments have been found in archaeological contexts dating back to prehistory (Spikins 2013; Spikins 2010; Oxenham et al. 2009; Sugiyama 2004), let alone the 18th century. Even his statement that "religious settings such as churches and cathedrals are worthy examples of vulnerable environments" (Pearne 2011, 202) where accessible facilities would encroach on the original aesthetic of the building is wrong. Religious settings, especially churches and cathedrals, were pilgrimage sites for all people, disabled and nondisabled alike in the medieval world (Chace 2017). True, they may not have conceptualised disability and accessibility in the same way that we do in the 21st century, but to imply that disabled people were scrubbed from existence and banned from such central social spaces as churches is not only historically inaccurate but worryingly ableist from a disability studies scholar.

Pearne may be an extreme example, but he is not the only one who believes that conservation should win out over accessibility. Goodall et al. (2004, 354) put forward

a case for providing disabled visitors (by which they mean wheelchair users) alternative means of experiencing a heritage site rather than altering the fabric of the building. The 'alternative means' they suggest is some kind of visual tour of areas the visitors cannot access, such as a photo book or virtual reality model. Despite acknowledging that disabled people constitute a more diverse group than only wheelchair users, this is the only suggestion they provide for trying to bridge the gap between the apparently conflicting goals of access and conversation. Although theirs is certainly a valid suggestion, there are a great many other suggestions that could be put forward: touch tours, audio guides, even large print guidebooks offer ways to increase accessibility at a listed site without any encroachment on the historical fabric of the site.

Oddly, these disability scholars seem to be arguing for beliefs that only they hold. The current methodology for heritage conservation revolves around "constructive conservation." Historic England, then English Heritage, published several reports outlining the principles and examples of constructive conservation, calling it "a positive and collaborative approach to conservation that focuses on the active management of change in ways that recognise and reinforce the historic significance of places, while accommodating the changes necessary to ensure their continued use and enjoyment" (2013). In other words, it is less important to "freeze" a moment in a building's history and more important to keep it functioning and usable to its current audience.

Constructive conservation is not a theoretical concept either, but has been used effectively at multiple sites. Whitby Abbey, located in northern England, adapted Whitby Hall into a visitors centre for the Abbey using the constructive conservation method. Rather than tearing down the 17th century banqueting hall that had been deserted and, through disuse, become dilapidated, a steel framework was inserted within the Hall, allowing a modern 2-storey visitors centre to be built without damaging the historical fabric. Additionally, Coşkun points out that the "headland grounds were reworked to create a fully accessible setting which respected the historical significance" (2015, 6). Although they do not expound what "fully accessible" means, it does show that accessibility can be recognised and incorporated into a constructive conservation design.

Given constructive conservation, there should no longer be a battle between "preserving" an historical building and adapting it for accessibility. Not all accessibility measures need to be obtrusive, nor do all aspects of a listed building need to remain untouched by modern hands. Moreover, the idea that conservation must trump all is incorrect and discriminatory, and a great many accessibility measures are available that require little to no interaction with the historical fabric of a building.

## 3.4. Summary.

In examining the academic literature regarding accessibility, it is clear that although there is a prevalence of research on accessibility in tourism, and indeed, on accessibility in museums and heritage sites, little of it is focused on hidden disabilities. The research that does involve hidden disabilities focuses primarily on one or two types and also only considers a small portion of a disabled visitor's experience. Three distinct strands of accessibility research are prominent (current state of accessibility, proposals to increase accessibility, and current and potential barriers), but rarely do they overlap with each other. With these limitations in mind, my research has been designed to address all three strands whilst also incorporating a wider range of hidden disabilities.

 In the next chapter, I examine the current emphasis on Equality, Diversity and Inclusion in the heritage sector, discussing how my research can bolster these attempts at inclusivity where previous initiatives have failed.

# Chapter 4 – Equality, Diversity, and Inclusion in the Museum and Heritage Sector.

Having discussed the political and academic landscape of accessibility, it is important now to look at the wider landscape of inclusion in the heritage sector. There has been growing momentum for museums and heritage sites to become more inclusive in their audiences (Werner, Hayward, and Larouche 2014; Cerquetti 2016; Martinez 2020), to challenge wrongs of the past (Giblin, Ramos, and Grout 2019; Abungu 2019; Gelsthorpe 2021), and to have a more representative workforce (Jennings and Jones-Rizzi 2017; Eid 2018; Rende et al. 2021). However, this momentum has not always led to tangible, long-lasting change, and it is important to examine these successes and failures in order to ensure positive change takes place.

In this chapter, I review and critique various initiatives in the museum and heritage sector relating to Equality, Diversity and Inclusion (EDI) policies. First, I explain what EDI is, particularly in the UK. I then provide a general overview of some important disability-related initiatives that have occurred within the museum sector. As disability has seen less attention than other EDI initiatives (Bowens and Museums Association 2020), I then look to ethnicity-oriented initiatives, which have been more plentiful, to examine what lessons can be learned from their successes and failures. Finally, I discuss why past initiatives have not produced the sector-wide change that was hoped for, why current EDI strategies have greater potential for this change, and where my research fits into this growing body of theory and practice.

## 4.1. Equality, Diversity, and Inclusion.

When this research began, formalised inclusivity in the heritage sector was still finding its feet (Andermann and Arnold-de Simine 2012). Since then, multiple events have occurred to precipitate the need and desire for policies that actively work to include traditionally excluded populations. A turning point that many point to is the

murder of George Floyd in America (Jackson 2020; Museums Association 2021; Leeds Museums and Galleries 2022), which started a cascade of social uprisings, including the Black Lives Matter movement (Cappelli 2020; Thelwall and Thelwall 2021; Bourdreau, MacKenzie, and Simmons 2022). Leeds Museums and Galleries, one of my case study organisations, references this event as a catalyst for the development of their EDI strategy, stating that "the murder of George Floyd by a police officer in Minneapolis on 25 May 2020 and the disproportionate impact of Covid-19 on black and ethnic minority people, have intensified LMG and Leeds City Council efforts to take further action to oppose racism (historic and present day) in all its forms and ensure that our practice truly reflects the diversity of the society we serve" (Leeds Museums and Galleries 2022, 8). Leeds Museums and Galleries is hardly alone in recognising the need for a more inclusive and diverse society, and multiple heritage organisations, as well as other sectors, have identified EDI as an important strategic strand in their recruitment and employee retention process (Natural History Museum 2021; National Trust 2022; English Heritage 2023).

In the UK, EDI research covers more than just disability studies, relating to all protected characteristics as defined under the Equality Act, discussed in Chapter 2 (2.1). As a reminder, protected characteristics include, among other characteristics, disability, age, and ethnicity (Equality Act 2010), and no one may be discriminated against because of these characteristics. To date, most research regarding EDI development has focused on ethnic equality in regards to staff demographics (e.g., Jennings and Jones-Rizzi 2017), visitor demographics (e.g., Werner, Hayward, and Larouche 2014), and especially representation within museum collections and exhibitions (Dodd et al. 2004; 2008; Research Centre for Museums and Galleries 2012; 2014). There has been some EDI work done regarding disability inclusion within the heritage sector, particularly by the University of Leicester Museum Studies department (see more on this below), as well as organisations like VocalEyes. I will try to focus on disability-centred EDI initiatives within the museum sector, but will naturally have to expand and appraise initiatives relating to other protected characteristics.

## 4.2. Disability-based EDI.

Disability-centred EDI initiatives are still few and far between in the museums and heritage sector, and tend to focus on diversifying museum staff and increasing disabled representation in museum collections and exhibitions. In this section, I examine some of this pioneering work.

### 4.2.1. Increasing Disabled Staff.

One of the earliest and longest-running diversity schemes was the Diversify initiative, pioneered by the Museums Association and initially sponsored in part by University of Leicester. Running 1998-2011, 130 participants took part, receiving training for 1-2 years, "combining a university museum-studies masters qualification with a varied amount of paid work experience" (Davies and Shaw 2012, 2). At first, the initiative focused on recruiting people from an ethnic minority background to the programme, widening to include disabled people since 2008. The goal of the programme was to "make museum careers more accessible to people from Black, Asian and Minority-Ethnic (BAME) backgrounds through targeted 'positive-action' training to prepare them to apply successfully for jobs in museums" (1). It also had a longer-term goal of increasing the number of minority-ethnic people in mid- and senior-level management roles in museums (1) and has been widely lauded as one of the most successful and impactful diversity initiatives within the sector (Jacobs 2011, 2).

In reflecting upon the outcome of Diversify, Shaw importantly observed:

> Diversify did achieve more than the sum of its parts by encouraging museums actively to consider the value of a diverse workforce. But it has not altered the views of governing bodies and museum directors enough to make them change their wider thinking, their policies and processes or, in particular, their approach to recruitment and selection. (2013, 11)

She found that although 98% of participants who responded to a survey "felt that Diversify had either been 'very important' or 'important' to them starting a career in the museum sector" (4), there is still a severe lack of diversity within the museum workforce. This, in turn, challenged the Museums Association, as the creator of the programme, to look deeper into why Diversify had "not necessarily translated widely into changes in organisational cultures or practices" (13). As is discussed below, they realised that change must be on an organisational level, not on an individual

level, and that the sector needed to "move away from relying on specific projects and initiatives" (18) and instead embed diversity within their practices more strategically.

Shortly before the end of Diversify, the Museums Association commissioned a report to understand *why* there was such a lack of diversity amongst museum staff. Maurice Davies (2007, 10), who carried out the research and wrote the report, uncovered a great many barriers to entry into the workforce, including unintentionally discriminatory hiring practices. In order to address these barriers, he realised that "sector organisations, including the Museums Association and the Museums, Libraries and Archives Council, play only a very small role in entry to the workforce. They will have to play a part if things are to improve, as will Creative and Cultural Skills and university museum-studies courses" (7).

The Museums Association took this call to action seriously, and has since become a driving force in advocating for positive change within the heritage sector. Within their founding documents, they specifically cite that one of their core values is to "champion diversity and equality" and "campaign for social and climate justice" (Museums Association 2023b). Their subsequent work has shown how committed they are to these values, particularly with their decolonising museums campaign. Their decolonisation work focuses on recognising and addressing the role of empire in the creation and maintenance of museums and their collections (Museums Association 2023a). Through the development of online resources, seminars, training programmes, and other tools for museums and heritage organisations to use, they have not only encouraged museums to take next steps towards more inclusivity, but have given them the support and knowledge to do so (Museums Association 2022). A particularly impactful case study is that of the Powell-Cotton Museum, which is built around the personal collections of English hunter and explorer Percy Powell-Cotton. With support from the Museums Association, the museum has shifted focus from the Powell-Cotton family to the cultures and people that Percy encountered and who supported him in his explorations and at home (Museums Association 2022). In doing so, they have created a far more inclusive collection with more diverse voices and stories than they had before. Work is still ongoing as well, to further decolonise their collections and co-create new exhibitions

to, as they say, "bring these silenced voices back into the building permanently" (Museums Association 2022).

It is true that they currently have no campaign that specifically focuses on disability inclusion, but their workforce campaign does include EDI advocacy in addition to other concerns such as pay, conditions and well-being. As seen in their decolonisation work, there is not only great potential for the MA to address inequalities in the sector, but also evidence that they have begun to do so.

## 4.2.2. Increasing Disabled Representation.

Whilst Diversify and the Museums Association have focused on increasing disabled staff through the industry, there has also been work on representation of disabled people within museum exhibitions in the UK. A significant amount of this work has been carried out by the University of Leicester's School for Museum Studies, but more recently, there have been other initiatives to include disabled people's experiences, particularly through History of Place and its subsequent programme Curating for Change, which I discuss below.

The University of Leicester's School for Museum Studies has long been seen as the heart of research into disabled representation in collections as well as championing co-production with disabled people to explore and create these representations. They have had significant impact on the industry as well, particularly in amplifying disabled voices in temporary exhibitions. A recent report states that their "work is highly valued for enabling and supporting the sector in navigating the challenges of embedding equalities practice" (Shepley 2020, 15). I myself have taken great inspiration from their insistence on centring the lived experience of disabled people, and owe a great deal to their research.

In particular, the School (and its associated Research Centre for Museums and Galleries, referred to as RCMG herein) has highlighted the need for more disabled representation in museum collections, explaining the need for such representation in their ground-breaking project Reframing Disability Representation: "Representation - seeing ourselves in cultural forms - matters; it changes people's lives" (Dodd et al. 2008, 22). An earlier project, Buried in the Footnotes, found that there was no lack of

disability-related material housed within museum stores, rather that there was a lack of understanding in how to sensitively and appropriately display these materials (Dodd et al. 2004, 5; 2008, 10). Reframing Disability Representation, as well as other research projects from the School, focused on representing the disabled experience in museum collections, particularly through co-production with disabled people. Indeed, their evaluation of the Reframing Disability Representation project showed that "many left the museum talking about disability differently, in ways that reflected the project's overarching aim" (Dodd et al. 2008, 163).

Acting on the UPIAS' mantra "nothing about us without us," RCMG has always been a leading proponent for amplifying the voices of disabled people through co-production. Disabled people are always part of the process, whether as consultants (Dodd et al. 2008, 46), direct contributors (35), or as co-creators in the actual interpretation and final exhibition design (52). More recently, in partnership with the Wellcome Collection, a new permanent exhibition, "Being Human," has been designed with consultation with various disability experts to de-medicalise and re-humanise what it means to be human, including the experience of being disabled (Forde and Barlow 2020). Kate Forde, Head of Exhibitions for the Wellcome Collection, and Clare Barlow, Project Curator for Being Human, even acknowledge that it was RCMG's work on a previous exhibition that encouraged them to reach out and partner with them in designing this new exhibition. Shepley noted that many involved with RCMG, both as individual participants and as partner institutions, reported "the impact of RCMG work on people with lived experience of disability and on museum professionals who are working on disability projects without this lived experience" (15). Without a doubt, RCMG is an industry leader in co-production with disabled people.

However, within all these projects, the outcomes are still aimed at a non-disabled audience. In reading through their evaluation literature, the vast majority of comments are from non-disabled museum visitors who have interacted with their exhibits (Dodd et al. 2008, 141). Throughout the whole of their nearly 180-page report on Reframing Disability Representation, there are a total of three mentions of accessibility - and none of these mentions are particularly in-depth.  For example, in explaining the accessibility of the museums involved, RCMG merely states "all

museums were accessible and provided information in a range of formats" (10). One of the most basic principles of accessibility is that no place is fully accessible and details are required to determine how accessible a site is to a disabled person (Cock et al. 2018, 13). To simply state that "all museums were accessible" is not only an oversimplification, it minimises the importance of accessibility, further prioritising the experience of non-disabled people.

That of course is not to diminish the importance of their work, particularly in emphasising co-creation with disabled people. In fact, heritage organisations that have worked with RCMG see them "as an ally who, through high quality research, creates sustainable links and who makes an impact through high-profile projects that benefit wider inclusivity in the cultural sector" (Shepley 2020, 26). The significance of RCMG's work cannot be overstated, as they have encouraged more disabled representation in exhibitions and also the importance of co-creation with disabled people in these exhibitions.

Another organisation that is championing co-creation with disabled people is Accentuate, in their past project History of Place and their current project Curating for Change. History of Place was a project that "revealed the presence and place of disabled people in relation to the built environment. These stories were told through the authentic voices of deaf and disabled people who founded, attended, visited and influenced building design and use from the Middle Ages to the present day" (Accentuate 2018, 8). They partnered museums with local disabled people and disability groups to research, design, and create these exhibitions, even if they erroneously state they are "the first project of its kind" (8) - something that RCMG has been doing for well over a decade.

The partnership between Accentuate and the museums they worked with was another avenue to explore and increase accessibility. They explain they "also wanted to tackle some of the barriers deaf and disabled face when engaging with heritage. A crucial part of this was to provide training to heritage sites, event organisers and museums. This training helped people to recognise the barriers deaf and disabled people face as well as consider how best to address these" (Accentuate 2018, 23). Additionally, "Our accessible approach has been so successful that we created two

toolkits based on our experiences to share learning with museums and cultural organisations" (33). The History of Place project goes a step beyond many of the RCMG projects in that it prioritised the inclusion of disabled people *as visitors* in addition to co-creators, thereby allowing disabled people to explore their own history rather than being excluded from it.

In explaining the importance of co-creation, Accentuate states that "by engaging with deaf and disabled people in the design and creation of exhibitions, films and digital games, it is possible to deliver accessible experiences that authentically describe their histories from their perspective" (2018, 4).For example, video games created through this project included audio description, subtitles, and BSL (20) - features that are rarely available in mainstream video games, let alone games created in the context of a museum.

I discuss their newest initiative, Curating for Change, in Chapter 3, explaining that it will provide placements for sixteen disabled people, giving them practical experience in the heritage workforce and theoretically paving the way for more disabled inclusion in the museum sector. Curating for Change is a direct result of History of Place, and is seen as the next step in bringing disabled people into heritage. Where History of Place was about co-creation, with museum professionals working alongside disabled people to create these exhibitions, Curating for Change is about training disabled people *to be* museum professionals. Accessibility is likewise embedded within this programme, with Accentuate pointing out that "exhibitions and displays are predominantly designed for 'normal' bodies, with minimal consideration given to how D/deaf, disabled and neurodivergent people will navigate and/or experience them" (Accentuate 2018, 4).

Furthermore, Accentuate recognises that Curating for Change promises *change*, and they hope that "these placements will begin to embed change within museums, generating learning to be shared more widely across the sector" (4). Given the prominence of many of the museums taking part in the programme, such as the Pitt Rivers Museum and the Ashmolean in Oxford and the National Railway Museum, and the current trend of implementing EDI strategies, there is great potential for change within the sector for Curating for Change, which is running from 2022 to

2024, to fulfil its aim of "greatly increas[ing] the number of disabled people visible in the sector" (Accentuate 2023). Sixteen disabled people perhaps does not seem like a huge increase, but the visibility of the project and the cultural atmosphere of today means that more disabled people will be encouraged to enter the heritage sector. As Shaw points out, "lack of diversity in the profession discouraged people from different backgrounds from aspiring to enter it, perpetuating the imbalance" (Accentuate 2021, 5).

Although they are largely similar, there is a subtle difference between RCMG and Accentuate in the final goal of their projects. For RCMG, their exhibitions aim to positively change cultural ideas of disability and disabled people's place in history (Dodd et al. 2008, 12). For Accentuate, they "set out to be fully accessible and place deaf and disabled people's heritage front and centre within museum programming" (Accentuate 2019, 9). RCMG is arguably aimed at nondisabled people; Accentuate is aimed at disabled people. Neither is inherently better, as both branches are important to the inclusion of disabled people, and ultimately, both feed into each other. By influencing nondisabled people to have a more welcoming view of disabled people, they encourage nondisabled people to notice accessibility. By ensuring exhibitions are fully accessible, disabled people are more visible as visitors and bring nondisabled people into contact with them, creating more positive attitudes towards disabled people.

## 4.3. Lessons from Ethnicity-based EDI Initiatives.

As previously mentioned, the Museums Association's Diversify initiative began as a way to increase the number of minority-ethnic staff in the museums and heritage sector. Indeed, the relative (if limited) success of that initiative has left a lasting impression on the sector, and there are many lessons to be learned from not only Diversify, but other ethnicity-based EDI initiatives. In addition to the Diversify initiative, other programmes include:

- Inspire Fellowship Programme - "for aspiring culturally diverse curators" (Iniva 2006)
- Change Makers - increasing cultural diversity of senior leaders (Arts Council England 2018)

- Black Blossoms - showcasing artists from diverse backgrounds (Black Blossoms 2023)
- Black Curators Collective - forum for Black women and non-binary curators (BBC 2021)

In 2022, a report combining research from Museum X and Culture&, both Black-led organisations, was funded by the Arts Fund to "assess the impact of ethnic diversity initiatives on the curatorial workforce in the UK arts and heritage sector" (Art Fund, Culture&, and Museum X 2022, 6). Broadly speaking, the initiatives had little impact, leading the authors of the report to comment "there is a deeply frustrating structural lag in the diversification of staffing at our national museums and galleries'' (3), a sentiment echoed by other minority groups in the sector (Bowen and Museums Association 2020). They discovered that there were still structural barriers that prevented minority-ethnic staff from either progressing or even entering the workforce, much like Shaw's examination had in 2013 (14).

In addition to conducting their own qualitative survey with 40 museum professionals in curatorial positions, the report examined a large number of previous diversity initiatives in the museum and heritage sector, including the Diversify initiative discussed above. The results of the examination were that diversity initiatives were inconsistent at best, with the impact being largely dependent on "who in the institutions was initiating and organising [the initiative] and the intentionality of their overall ambition" (Art Fund, Culture&, and Museum X 2022, 56). In other words, and as evidenced elsewhere in their report, without support from senior management nor specific targets, these initiatives "can only have had minimal impact of diversifying the demographics of the UK curatorial sector" (56). Despite admirable intentions, significant change has yet to take place. In fact, the report reveals that any change that has been achieved "has been largely due to individual personal drive and ambitions rather than the programmes themselves" (7).

With a lack of structural support, professionals from minority groups instead created peer-to-peer networks, a significant one being Museum Detox. This particular network was founded for and by museum professionals of colour with the aim to

"empower and support each other to heal, to be ourselves, and to reclaim our history" (Museum Detox 2022). There is less of an outward advocacy emphasis to the network, instead creating a safe space for members to set aside many of the pressures that come from working in such a predominantly White industry. Indeed, their impact has been largely as a support structure, with one report revealing that "Museum Detox was noted by a number of respondents as being a key source of peer support and encouragement, assisting its members in dealing with difficulties they face as employees in arts and heritage organisations" (Art Fund, Culture& and Museum X 2022, 57).

If one thing can be learned from these ethnicity-oriented initiatives, it is the importance of peer-to-peer networks to provide support. The Disability Collaborative Network (DCN) was created to provide such support, although not quite in the same way as Museum Detox. There is more of an emphasis on sharing best practice amongst museums at DCN, but they did attempt to launch a network specifically for neurodiverse museum professionals in 2018 (Disability Collaborative Network 2023). Unfortunately, the network no longer seems to exist. Since then, the Neurodiverse Museum has been created, with an aim to create such a network for neurodiverse people as well as advocate for a shift in how museums view neurodiversity (The Neurodiverse Museum 2023).

## 4.4. Discussion.

In examining even the most successful of these EDI initiatives, one thing is clear: increasing diversity within the industry has been a slow and limited process. Even ethnicity-based initiatives, which have had the most momentum and arguably the largest impact, have not brought the heritage industry up to representative levels (Art Fund, Culture&, and Museum X 2022). In 2013, Shaw noted that "If the museum sector is working towards a representative workforce, the percentage of museum staff from minority-ethnic backgrounds should be around 12%, not 7%" (13). Unfortunately, this number has not increased, but has actually decreased, with only 6% of the museum workforce coming from a minority-ethnic background in 2022 (Arts Council England 2019, 8). Ali and Byrne, in their 2022 analysis of "the micro-institutional ways in which diversity is performed" (1) in the museum and TV

production industries, determined that "diversity schemes [are] a 'quick fix'" (3) and that "using umbrella terms such as diversity undermines the complexities of addressing different and intersecting inequalities" (5). This is in direct contrast to Shaw's conclusions nearly a decade prior that "positive-action training is not intended to have an immediate impact, but to create long-term changes in the workforce" (2013, 12). Unfortunately, this advice has not been heeded, and the sector has suffered for it, relying on "quick fixes" instead of using these diversity schemes to critically examine barriers to participation and embed the importance of equality and diversity within their organisations.

In reviewing previous EDI initiatives, I must agree with both Shaw and Ali and Barnes. Originally, these programmes were created to enact long-term change by initiating first steps, by actively removing barriers for diverse people to enter the museum and heritage workforce. However, they were only ever intended to be short-term, relying on institutions to do the work of embedding lessons learned from participation in these programmes. Shaw writes:

> Institutions need to accept responsibility for diversity and ensure it is championed right at the top, starting with the governing body. The role of leadership in creating an environment that supports inclusive working practices is paramount. The people at the top determine priorities, set strategy and create policies for the whole organisation. If museum leaders don't take action, change will be limited (Shaw 2013, 14)

This is why I was so keen to examine the organisational structures of my case study sites - by examining these structures, it would be easier to understand the organisational barriers to implementing accessibility. Within my case study organisations, I did not find a lack of enthusiasm for accessibility. Indeed, I found quite the opposite; each organisation was eager to increase accessibility, but they were unsure how to do so (see Chapter 10). Additionally, at the beginning of my research, there was little to no institutional policy that outlined the importance not only of accessibility but of inclusion more generally. Since then, all three organisations have published or are in the process of publishing EDI strategies, which I discuss below in 4.4.2 - these policies represent the start of accepting responsibility and moving forward to a more inclusive future.

### 4.4.1. Lessons from the Past.

The most important lesson from previous attempts at diversity is that organisations must commit *internally* to increasing diversity. This may seem paradoxical, as the above evidence shows that past initiatives have done little to increase diversity in the museum sector. However, the difference between this suggestion and past initiatives is the emphasis on an *internal* commitment. Shaw points out that "having more projects and initiatives is not the answer. There needs to be a more holistic approach that tackles all the barriers to change" (2013, 4). For change to occur, there cannot be an external group providing "diversity hires" for an organisation. All the motivation and impetus must come from the organisation, which then has a greater likelihood of translating intention into long-term change. As Ali and Byrne point out, "diversity schemes as a route for implementing diversity in the institution… are seen as practical, though insufficient, first steps" (2022, 17-18). In "It's about handing over power," the authors likewise point out that "from the most recent quantitative data… these programmes can only have had minimal impact on diversifying the demographics of the UK curatorial sector" (Art Fund, Culture&, and Museum X 2022, 56). The same paper found "a lack of prolonged investment and a lack of institutional strategy which means schemes are segregated and fail to achieve more structural changes. Diversity schemes are often problematically understood as a one-way stream, benefiting only the ethnically diverse 'recipient'" (13). I will return to this problematic, paternalistic view below, but it is clear that these initiatives rely too heavily on temporary outside influence and do little to change the internal culture of an organisation.

Because of this lack of attention, there is a suggestion that sometimes, these initiatives do as much harm as they do good. In discussing the Diversify programme, reviewed above, the authors write "little attention given to the organisational culture of the host organisation, nor to how existing staff would feel about having a trainee placed in the organisation. One interviewee described being questioned by staff in the host organisation about why she had been given this opportunity, which forced her to respond she had been chosen because of her ethnicity" (Art Fund, Culture&, and Museum X 2022, 41). As I discuss in Chapter 8, many of my participants disliked the idea of having to disclose their disabilities, as it may invite negative biases

towards them and therefore have a negative impact on their experience. Likewise, this interviewee had to disclose their ethnicity and that their position in the organisation was solely based on that characteristic which in turn impacted her experience.

As mentioned above, there is an implication that these schemes are only beneficial for the "diversity hire" - they are being given an opportunity that they would not otherwise have due to the benevolence of the organisation. This speaks to a paternalistic attitude within these organisations. As Ali and Byrne (2022, 13) write, "institutions perform acts of inclusion to maintain their 'morally good' status," making these inclusions little more than empty gestures. It feels as if museums are trying "to make pro-diversity sound like a positive action, rather than a response to historical exclusion" (Minott and Museums Association 2020), meaning they are not engaging with the difficult work of dismantling existing power structures that benefit a more traditional, exclusive workforce. Framing diversity as a "morally good" thing to do presents "a danger of indulging in self-praise – praise that echoes paternalistic behaviours of the past, casting the institutions as benevolent and visitors as passive recipients of grace" (Minott and Museums Association 2020).

For this reason, many museum organisations such as the Museums Association and Museum Detox are calling for museum and heritage organisations to not only become passively inclusive, but actively anti-discriminatory (Museum Detox 2022; Museums Association 2023a). Anti-discrimination is the process of not only repealing discriminatory practices, but embedding practices that work towards equality. The Equality Act, with its provision of "reasonable adjustments," is an example of anti-discrimination work, as is the example above of the Powell-Cotton Museum. In each of these instances, steps are taken towards more inclusion, actively reaching out to underserved and underrepresented populations and addressing barriers to their engagement. In this context, much emphasis is placed on anti-racism and decolonisation work - something that makes sense in the current political climate - but the same change to active anti-discrimination applies to disability inclusion and accessibility as well.

Additionally, these schemes can reduce brilliantly capable people to mere statistics. Harkening back to the example above where a participant was forced to disclose that they were part of a diversity scheme, they were suddenly reduced to their ethnicity with other staff members "seeing them through the limited prism of their ethnicity and amplifying that at the expense of professional development and career progression" (Art Fund, Culture&, and Museum X 2022, 14) and judging them "as 'out of place' and potentially inferior" (13). Not only do existing staff members question the validity of a "diversity hire," but Ari and Byrne (2022) found that "these diversity schemes can invite self-doubt about one's own skills and contribution to the sector, or what was described as an 'imposter syndrome'. Thus, paradoxically, even though these schemes are designed to empower ethnically diverse creatives and cultural workers, they can contribute to a sense of insecurity" (14).

Part of this insecurity comes from inorganically forcing participants of diversity schemes into an institutional culture that is not necessarily open to their inclusion. The heritage sector is overwhelmingly white, middle class, and non-disabled (Arts Council England 2019), something anecdotally confirmed at my case study sites. Because of this privileged background, many institutions have a hard time seeing their own biases, meaning that "the cultural whiteness of most institutions they [participants in diversity schemes] access and the structural inequality of the sector as a whole make these spaces alienating" (Art Fund, Culture&, and Museum X 2022, 18). This alienation can be seen in acts such as the above example - questioning the presence of an ethnically diverse new member of staff - as well as more common practices such as standard holidays based on the Christian calendar. In other words, organisations are ignoring the strengths that diversity brings and instead pressuring staff to fit into a predefined mould - "at best, failing to recognise the value of an ethnically diverse workforce beyond their ethnicity, and, at worst, reproducing discriminatory and racist attitudes and practices" (14).

By forcing people to fit into an existing institutional culture rather than encouraging the culture to embrace diversity and adapt, these institutions are creating an additional burden for participants in diversity schemes, which is the opposite of what these schemes are created to do. There is an incredible amount of internal work required to "pass" in a discriminatory system, often referred to as 'emotional labour.'

Ari and Byrne (2022) found that participants in diversity schemes "have to negotiate myriad racial, cultural and social codes and practices that at best leave them drained and at worst push them outside of the sector" (13). Worse, because of the paternalistic attitude, many people in this position are expected to be grateful because they are being given an opportunity that they would not otherwise have access to and thus have no right to complain about discrimination or less than desirable conditions. Networks like Museum Detox and DCN have proven to be an important support system for certain heritage members, but there continue to be calls for "an acknowledgement and open dialogue with everyone involved about the emotional labour it takes to contribute" (Art Fund, Culture&, and Museum X 2022, 31).

Emotional labour is not limited to participants, either. Ari and Byrne (2022) discuss how "the work to diversify the sector is falling on the shoulders of ethnically diverse people, which can add to the fatigue they experience and increased workload which might affect progression ambitions and have ramifications on their emotional and mental wellbeing" (15). It seems as if, when internal schemes are organised, they are driven by an individual - more often than not, one of the "ethnically diverse employees in the organisation" (15) - rather than by a shift in the organisational culture. Because these internal schemes are the result of only a small number of staff members, there is a lack of support from the wider organisation or even senior management, which again makes it difficult for wider change to occur. As Shaw (2013) pointed out 10 years ago, "There needs to be a shift in emphasis from the individual to the institution, with organisations as a whole recognising their responsibility for workforce diversity" (10).

### 4.4.2. Progress and Change.

EDI strategies are where institutional responsibility is codified. The Museums Association published their EDI policy in 2020, providing a framework for other organisations. As discussed above, the Museums Association is seen as an industry leader and their policy includes how they define "equality," "diversity," and "inclusivity" as well as specific responsibilities for various segments of senior leadership, including the Board of Trustees (Minott and Museums Association 2020). There are also specific procedures and outputs outlined, plus how often the policy

will be reviewed. For the most part, it is a standard policy document, which is important in positioning EDI alongside any other significant policy in a heritage organisation. The standardisation means that EDI is not a trendy new idea, merely one that is finally gaining the attention it deserves and thus can be treated like any other policy, with the same mechanisms to hold institutions accountable.

Of my three case study organisations, both the National Trust and Leeds Museums and Galleries have a published EDI policy on their website. Whilst York Archaeological Trust does not currently have one published, this is because the policy is currently being put together - I am on the team that is creating the document. There is a strong dedication within YAT to create this document, and because of my background, there will likely be an emphasis on the inclusion of disabled people within the document. In time, this policy will be available on our website in line with best practices as set out by the Museums Association.

The National Trust EDI document (2022) is more detailed than the Museums Association policy, partly because the document also includes what they are currently doing in regards to EDI, complete with case studies, as well as future programmes and specific goals. Happily, alongside initiatives aimed at ethnic equality, religious diversity, and LGBTQ+ representation, there are several specific mentions of accessibility throughout the document. For example, they specifically mention "improving the consistency of the accessibility information we offer online and in our handbook, as well as improving our website and app so they're accessible for all users" (6).  This is incredibly refreshing, as the Museums Association policy does not mention accessibility at all. As I discuss below, disabled people have a different experience of inclusion, as there are physical barriers in addition to attitudinal barriers that continue to exclude them from museums and heritage. Therefore, the specific mentions of accessibility, both in their case studies (8) and in their future goals (3), is encouraging. There is a concrete dedication to disabled people that is often lacking in many EDI documents.

Leeds Museums and Galleries have a detailed EDI policy as well, focusing especially on where they can improve, how they will improve, and a timeline of when and how they will report on these improvements. Like many EDI documents, there is

very little mention of accessibility, though they do include a general "improve our accessibility" (16) aim. The lack of specificity of this particular aim is somewhat disappointing, as it remains too vague to truly measure improvement. However, most of their outcomes and goals are related to ethnic equality - something that does make sense, given that Leeds is an incredibly ethnically diverse city.

One thing the National Trust and Leeds Museums and Galleries policies have in common is the measurable targets that they lay out. Ari and Byrne (2022) suggest "adding realistic and actionable targets, review dates and accountability measures" (11) to EDI policies, something that both National Trust and Leeds Museums and Galleries do in their documents. Leeds Museums and Galleries especially lays out how they will report their progress, as well as specific methods for achieving each of their outcome goals (27) shown below in figure 2. By laying out precisely how they will report their progress and also publishing their EDI policy to the general public, they are inviting members of the public to keep them accountable and to push them in achieving these goals.

**What we collect and when we report:**

| Regularity | Data | Audience | Format |
|---|---|---|---|
| Monthly | Service and site-specific quantitative data | LMG / LCC | Dashboard: managers' forum and staff newsletter |
| Quarterly | Service and site-specific quantitative data enriched with qualitative data that shows impact on communities and individuals | LMG, LCC, ACE | ACE quarterly report<br><br>Presentation to oversight board |
| Annual | ACE annual audience data, KPIs and case studies | Internal and external stakeholders<br><br>Museum sector<br><br>Funding bodies | Submissions to Audience Finder dashboards, plus annual report<br><br>Ward advocacy reports<br><br>Annual staff conference |
| Bi-annual | LMG audience research | LMG<br><br>Internal and external stakeholders<br><br>Museum sector<br><br>Funding bodies | Individual venue reports, and LMG report |

*Figure 2. Data collection and reports for LMG (taken from Leeds Museums and Galleries 2022, 27)*

Likewise, the National Trust document also outlines how they will measure their progress, though they are not as detailed as to how they will publish these results.

*Figure 3. How National Trust will measure their progress (taken from National Trust 2022, 9).*

It is important to note that they specify that their initial goal is creating a more inclusive organisational culture. As discussed above, if the inclusive culture is lacking, it is difficult to make any lasting progress in EDI.

Something lacking in both the EDI policies of the National Trust and Leeds Museums and Galleries is specific quantitative targets, although this may be because many of the stated goals are more qualitative than quantitative in nature. However, if any organisation prioritises increasing the diversity of their staff and volunteers, there must be numerical targets in mind - or at least a numerical representation of the organisation status quo to understand improvements. In discussing EDI policies, Ari and Byrne (2022) observe that these targets "remained mercurial with one senior member of the staff commenting: 'I think it's definitely an abstract goal'" (11). It is worrying that even a senior staff member sees these goals as abstract, and perhaps maintaining EDI demographics and statistics is a way to concretise the abstract. The

museum sector already maintains visitor demographics as a way to measure visitor diversity, and Ari and Byrne point out "there was considerable emphasis in staff meetings on the numerical and demographic profile of visitors to showcase diversity (11)" in their ethnographic research. Likewise, there have been calls for "diversity targets on staffing and audiences" (Arts Fund, Culture&, and Museum X 2022, 23), but this has been made difficult by the fact that the DCMS has not published any targets for cultural organisations to aim for.

However, as with any other policy created by an organisation, simply writing a policy is not the same as enacting it. As Ari and Byrne (2022) put it: "Policies can be a statement of intent – or guidance intended to ensure legal compliance with the Equality Act. But they do not necessarily have an impact on practice" (12). Once these policies are in place, there must be action. That is why targets are important - but as seen by earlier initiatives (and emphasised in the National Trust policy), there must be a change throughout the whole culture of the organisation for these policies to be effective.

In order for an organisation to truly commit to a cultural shift, these strategies and themes must be discussed regularly and by staff and volunteers at all levels. As of right now, there seems to be a lack of this daily engagement, as Ari and Byrne observed "through our institutional ethnography, explicit engagement with diversity as a policy or strategic aim was largely absent, lost in the more pressing business of the institution" (12). Thus far in the cultural sector, pushes to increase diversity have been a top-down goal without any input from people who actually engage with the public or have influence over hiring practices. There needs to be dialogue between all levels of management as well as between all teams within an organisation in order for people to not only understand these changes but the impetus behind them.

When examining my case study sites, I believe that two out of the three sites are primed for a cultural shift amongst their staff. At both Abbey House and Barley Hall, front of house members are able to offer suggestions to more senior staff and in many cases, these suggestions are put into practice. As I discuss in Chapter 9, there is an open, fluid flow of communication between staff of all levels and belonging to all teams which has led to accessibility improvements. Naturally, there will be difficulties

in the implementation of these policies, but at both of these sites, I already encountered an attitude of inclusion towards disabled people, and I believe that this same attitude of inclusion will eventually be extended towards all protected characteristics. Particularly at Leeds Museums and Galleries, there is already a significant focus on ethnic diversity and inclusion, which gives me confidence that they will succeed in their cultural shift towards inclusion.

The National Trust, as testified to in my interviews with Dr Heather Smith, Equity Officer for the National Trust, is striving to achieve such a similar cultural shift. There are several initiatives being implemented to support the EDI strategy, which I discuss in Chapter 11, and these initiatives are internally-focused with measurable outcomes and importantly, funding to improve accessibility. I believe the challenges I saw at Treasurer's House were specific to that site, rather than the organisation as a whole. The new EDI strategy will certainly help address some of these challenges, but I believe it will take more work at Treasurer's House in order to fully enact this strategy.

However, the breadth of these strategies highlights an important point when discussing EDI: disabled people have a very different experience of discrimination than people from other protected characteristics. In addition to attitudinal barriers, there are physical barriers that prevent disabled people from engaging with heritage, either as a visitor or as a professional. Reflecting on the Diversify project, "fellows with disabilities commented on the difficulties of achieving an appropriate balance between managing the symptoms of their disability and career ambition" (Jacobs 2011, 3). Ari and Byrne (2022) point this out as well, explaining that "whilst inequalities based on these social categories [aka protected characteristics] are all important, using umbrella terms such as diversity undermines the complexities of addressing different and intersecting inequalities" (5). Although they were discussing this in relation to ethnic equality and the danger of depoliticising ethnic discrimination, I argue that it is equally true of disability discrimination. Strategies that work to include the LGBTQ+ population may not help to include disabled people, and so these differences must be remembered when developing EDI strategies.

### 4.4.3. Importance of Accessibility in EDI.

In a report on the impact of the RCMG's work, one participant said:

> While discussions of diversity and inclusion are becoming much more prominent in certain aspects of museum work...disability remains pretty much invisible even in this context. When disability does come up, it is invariably about accessibility, with no acknowledgement or recognition of disability culture and identity or of disability art, and no understanding of the concept of ableism. (quoted in Shepley 2020, 6)

The wider message of this quote is important, that disability is underserved in most diversity work, but the dismissal of the importance of accessibility is interesting to note. This is why I focused so exclusively on accessibility within my own research. I have found many researchers exploring how to better acknowledge disability history (Dodd et al. 2008) or how different disabilities impact a visitor's understanding of a building (Schofield et al. 2020) or even how to dismantle barriers to employment for disabled people (Khan et al. 2019). However, at the heart of all of this work, there is an assumption that the work of understanding accessibility has been done. As seen in Chapter 3, however, the existing research is by no means exhaustive. Further study into accessibility is still critical for disabled people to take part in heritage, whether as a professional, a visitor, or some mix of the two.

My research will show that accessibility is not a "one and done" exercise; organisations must constantly seek out feedback from visitors and staff members to increase the accessibility of their sites. The same mindset permeates EDI research, that organisations must constantly review their policies and action plans to adjust as necessary in order to reach their targets. Accessibility research is just a small part of the wider EDI landscape, but it is a critical part that must not be overlooked if organisations are serious about including disabled people.

## 4.5. Summary.

As Ali and Byrne (2022) rightly point out, "there is yet a long way for diversity to be structurally embedded in the institutional life of cultural organisations, and it is only through this overhaul of institutional culture that we are to reach a more equitable sector" (18). Many previous initiatives have had only a limited impact on improving diversity and inclusion. However, the new emphasis on EDI strategies, making diversity and inclusion an enshrined policy amongst many heritage organisations, is

a hopeful turn towards this structural embedding. My research parallels much of what EDI scholars have said in regards to enacting these policies: consultation is crucial, communication across an organisation paramount, and it is not enough to be inclusive, an organisation must work to be anti-discriminatory.

In the next chapter, I explain my methodology, which was informed by these three strands of research within accessibility studies.

# Chapter 5 – Methodology.

In this chapter, I outline my methodology: how I gathered data, how I analysed it, and the various decisions that led to the overall research output. I begin with an overview of qualitative data processes and why qualitative research is the most appropriate option for me. I then explain my main framework for gathering data: focused ethnography. From there, I describe how focused ethnography is utilised with my participants, who all identify as people with hidden disabilities. Then, I outline my research design for gathering data from my case study organisations. Finally, I discuss my use of Critical Discourse Analysis to analyse the data I have gathered.

## 5.1. Qualitative Approaches.

This research relies exclusively on qualitative data collection procedures. I felt that a deeper analysis of the lived experience of my participants was preferable to a broad approach, as the range of hidden disabilities is vast and too ambitious for this research. Instead, by selecting a cross-section of people with hidden disabilities and learning from them, I sought to gain a fuller understanding of the barriers faced by my participants. My rationale for participant selection is described below (see section 5.2.1.3), but careful attention has been paid to ensure no one hidden disability type dominates the data and instead a deep, thorough understanding of each participant's accessibility needs is acquired.

There are many instances where quantitative data methods are particularly relevant to understanding the impact of disability, and have the potential to lead to changes that aid disabled people. For example, Kim and Lehto (2013) examined over 160 families of disabled children to determine motivations and activities when planning family trips. They developed a structured survey asking families to rank how much they agreed or disagreed with particular statements regarding their family leisure trips (2013, 15-16). These survey answers were then analysed and ranked to give researchers a clearer picture of these leisure motivations and activities. It was found that the primary motivation was to "develop children's physical skills and competences" (2013, 19) and their preferred leisure destination was an outdoor recreation area that required low energy levels, such as nature walks or bird

watching (20). These findings can be then fed to service providers, as the researchers themselves have suggested (Kim and Lehto 2013, 21-22), to aid in creating more appropriate disability-specific offerings as well as adapting existing activities to be more inclusive to the families of disabled children. Quantitative data are often utilised to gain a bigger picture of an issue, to determine the overarching themes such as the motivations and activities in Kim and Lehto's survey, and therefore to help enact change based on the findings.

In contrast, qualitative data are often employed to examine the nuances not evident in quantitative data-based research. Burns et al. 2009 used interviews and focus groups to gather qualitative data about the experience of disabled people when visiting outdoor landscapes, particularly woodlands. After recruiting participants, they they sought to learn about these participants' particular access needs in order to enable them to participate in the study's focus groups in the first place. Many sites had to be discounted as potential venues for the focus groups because of a lack of amenities, such as accessible toilets or visitor facilities, and travel arrangements had to be carefully coordinated (2009, 408). These challenges, the researchers realised, necessarily excluded many potential disabled visitors from participating in outdoor leisure activities. Through their focus groups, the researchers were able to tease out the importance and value of outdoor activities to disabled people. For example, they discovered that participation in the outdoors contributes to a greater sense of self, as it re-enforced their belief that "being disabled did not signal 'abnormality' or otherness" (2009, 413). By engaging in outdoor recreation, participants felt more normalised, even if they encountered barriers along the way. Such conclusions would be nearly impossible to reach using quantitative data methods alone, but become apparent through in-depth qualitative study.

Such nuanced understandings of disability and accessibility are at the core of my research interests. As such, I have designed my study around qualitative data gathering and analysis. The main method of gathering this qualitative data is through focused ethnography, which I describe below.

### 5.1.1. Ethnographic Study: Focused Ethnography.

Ethnography comprises the primary data gathering methodology underlying my research. As Hammersley (2018) rightfully points out, ethnography has come to mean a wide range of methods and theoretical models. For the purposes of this research, ethnography is taken to mean "the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting (if not always the activities) in order to collect data in a systematic manner, but without meaning being imposed on them externally" (Brewer 2003, 99). More simply, it is participant observation in the participant's natural setting, and extracting meaning through these observation-focused practices. Here, my focus is on participant observation of visitors with hidden disabilities negotiating a visit to a museum or heritage site, and I aim to reveal the barriers they encounter, as well as how the site itself can help to dismantle these barriers.

As mentioned in Chapter 1, data for this research have come from two distinct sources: the visitor's point of view, and the organisation's point of view. Both offer a unique perspective on issues of accessibility. Through a combination of interviews and participant observation, visitors with hidden disabilities highlight barriers that a nondisabled visitor may not notice. For organisations, using participant observation as well as interviews with front of house staff and management, I seek to reveal the practical difficulties of implementing these solutions but also whether the desire to implement them is even present in the first place. Through ethnographic study of both groups, I negotiate the needs of the two groups to find acceptable solutions, as well as the general attitude surrounding these changes. As my research reveals, it is not a simple matter of increasing physical access, but also of creating more welcoming environments in which such changes may be suggested. Practical details of my data collection activities are explained below.

Although most ethnographic studies are long-term and take place over a matter of years, this is not possible nor needed for my research, as described in more depth below in section 5.1.1.1. There is a more recent trend towards what Knoblauch (2005) deems "focused ethnography," which is characterised by shorter yet more

intensive periods of time in the field. Pink and Morgan (2013) expand this idea, identifying specific characteristics of focused ethnography: intensity in research encounters, a focus on detail, ethnographic-theoretical dialogue, and a reliance on audio-visual data. These are precisely the characteristics that define my research encounters, placing them firmly in the focused ethnography method of data collection.

### 5.1.1.1. Intensity in Research Encounters.

As a trade-off for shorter periods of field work, Knoblauch points out that "focused ethnographies are typically data intensive" (2005, 9), a point with which Pink and Morgan concur (2013, 12). A researcher spends less time embedding themselves into an environment, instead inserting themselves into the thick of action from the beginning (Pink and Morgan 2013, 7). By entering the fray in 'media res', the intensity of the encounters is produced: a researcher comes into the encounter with a specific purpose and a specific research agenda. In turn, this insertion method has several implications. A researcher must put in a considerable amount of research before they enter the field, and they must be selective in the participants and encounters they seek out. Also, when gathering data, the researcher must not be passive but rather take an active, interventionist role in situations. Here I mean that, for example, I did not wait for my participants to organically choose to visit a museum and then follow along, but rather I scheduled a museum visit with them to a specific site (see section 5.2.1 below).

### 5.1.1.2. Acquired Knowledge.

The acquisition of knowledge on the part of the researcher is key in focused ethnography. Both Knoblauch and Wall emphasize that a researcher may not enter into the field without any prior knowledge, as they may in traditional ethnography (Wall 2015, 6; Knoblauch 2005, 10). The researcher must put in their own amount of research and come to the situation with a level of background knowledge that allows them to quickly come to terms with the culture that they are studying. Very often, the researcher is already a member of the community, and therefore they have not only knowledge gleaned from more traditional academic sources, but also embodied knowledge that comes from existing in this particular setting (Wall 2015, 6; Higginbottom et al. 2013, 7).

In my research, my own background offers the needed baseline from which to pursue an in-depth, intensive study of heritage accessibility. I have several years of experience in heritage and specifically front of house positions in museums. I have worked for the York Archaeological Trust since late 2016 and formerly volunteered with York Museums Trust. I have an intimate understanding of the culture that develops amongst the front of house staff and how, although management at higher levels may have high ideals, these ideals can become watered down as practicalities set in. It is often the front of house staff members that negotiate between ideals and realities, as they are the ones that come into closest contact with the visitors at a site. For this reason, I entered my research with a desire to shadow front of house staff rather than management-level employees, as it is the front of house staff that wields the greatest amount of power in terms of shaping a visitor's experience, and I am intimately acquainted with these processes. As such, I can look closely at actions and words that others may overlook or disregard as insignificant. A simple example is the "script" that admissions staff use – I know from first-hand experience that whilst there is specific information that needs to be communicated to visitors, each staff member has a different pattern and style to how they present this information. The pattern and style in turn reveals the priorities of the staff member. By examining these scripts, I can understand the whether or not they emphasise accessibility.

As well as my experience in heritage and museums, I have extensive knowledge and training in accessibility. Both on an academic level and a practical level, I have a nuanced understanding of accessibility needs and how they shape both a museum visit and a person's identity. My Master's thesis concerned accessibility guides for museums and heritage sites, in which I laid out best practices for creating these guides (Fisher 2017). It also gave me an opportunity to dig deep into the effects of both positive and negative museum visits as shaped by accessibility needs. The interaction between identity and experience is complex, and someone without my background may not appreciate how a simple museum visit can have a profound effect on someone with a disability, in complex ways. Through my combined personal background and research interests, I fulfil this unique role of "both outsider and insider," as Wall describes it (2015, 6), enabling this focused ethnographic approach to prove fruitful.

Additionally, through the course of this research, I came to identify as disabled. Shortly before starting this PhD, I was diagnosed with anxiety, depression, and OCD and was put on medication for them. Because my impairments were hidden and seemed less severe than other disabilities, I was hesitant to adopt the label "disabled" for fear of upsetting people who were "more" disabled than myself. I did not identify as fully nondisabled, but rather somewhere in between. However, in interacting with my disabled participants and understanding that although their disabilities were hidden and therefore their day-to-day struggles were also often hidden, I was not appropriating a term that did not belong to me. I was reclaiming a term that deeply ingrained ableist attitudes had taken away from me. Taking medication is a way I manage my disability, but I have also come to recognise the fact that, even with medication, I am still limited in certain activities when my mental illnesses flare up. Interestingly, because I "became" disabled over the course of this research, I was "both outsider and insider" (Wall 2015, 6) amongst my disabled participants, again proving the focused ethnographic approach useful.

### 5.1.1.3. Selective Participants.

To be a successful "outsider and insider," a researcher must find participants that facilitate sharing of experiences. Higginbottom et al. describe participants in focused ethnographies as "informers" (2013, 3–4) because of the role that they perform in guiding a researcher through these specific encounters. The participants – or informers – already hold key information and experience, often without even realising it, and the researcher must draw out this knowledge through their shared encounters. This unknowing expertise has two implications: participants must be carefully selected prior to entering the field, and a researcher must necessarily use more interventionist methods of eliciting data. To the first end, Higginbottom et al. (2013, 4) call for "purposive sampling," or carefully pre-selecting participants for their "specific knowledge or experience which is judged to be of interest to the investigation". Likewise, Wall (2015, 4) points out that participants may not know each other, but they share a specific cultural perspective that is valuable to the research at hand.

In the case of my research, this means seeking out people with hidden disabilities as participants. Full discussion of my selection criteria is below. It would be of little use to me if a participant enjoyed visiting heritage sites but did not have a hidden disability. Likewise, organisations that are not committed to increasing their accessibility would potentially need to be convinced that they should increase their accessibility, which would in turn waste valuable time in the field. By selecting participants that already have a level of relevance for, and vested interest in, this project, I can gather meaningful data that yield better results in the restricted timeline of this research.

### 5.1.1.4. Interventionist Methods.

Not only must a researcher carefully select participants, they also must be more intrusive in their means of data gathering. Due to the limited time frame, it is not enough to stand back and simply observe, hoping for particular situations to arise. As Pink and Morgan (2013, 2) emphasise, focused ethnography "involves intensive excursions into their [the participants'] lives, which use more interventional as well as observational methods to create contexts through which to delve into questions that will reveal what matters to these people in the context of what the researcher is seeking to find out". For a researcher to get the data they need, they must ask specific questions or guide participants through specific scenarios, using semi-structured interviews, performative acts (like miming how to open a door), and similar methods. Wall (2015, 13) points out that the high volume of data that has come to typify focused ethnography is often because of these methods. Semi-structured interviews, a method that I rely heavily on with disabled participants (discussed below), are particularly suited to focused ethnography as they focus on particular knowledge that the participant shares rather than waiting for that knowledge to reveal itself naturally, as would happen in more traditional ethnography.

All of this adds up to a very data heavy, intense research setting. Every interaction has a purpose and intention, and every interaction is recorded and analysed as part of a data set. When I am in the field, there is no "down time": everything is active and deliberate. Focused ethnography does not suffer from its condensed time scale, as many critics often worry, but rather uses that time scale to create energetic, profound

interactions that then inform a researcher and provide deep, detailed data from which meaningful conclusions can be reached.

### 5.1.1.5. Focus on Detail.

Because of the shortened time span, researchers must also focus on gathering more specific details in a setting rather than on a more general overview. As Knoblauch (2005, 2) puts it, in focused ethnography, "instead of social groups or fields, studies focus on communicative activities, experiences by communication." Wall (2015, 3) describes this focus as dealing "with a distinct problem in a specific context and ... conducted within a sub-cultural group". I prefer this view of focused ethnography: I am addressing a specific problem (accessibility) in a specific context (museums and heritage sites) with a specific sub-cultural group (people with hidden disabilities). Because I am addressing a specific problem in a constrained amount of time, I must enter field work with specific questions in mind. Pink and Morgan (2013, 10) agree, saying that "the research questions need to be responded to more firmly", something that Wall also emphasises (2015, 12). To do this, the research questions must be clear and precise from the outset. I have discussed the general questions this research is asking in Chapter 1, but I also expound upon them below, matching each question to a particular setting and including further, appropriate questions.

### 5.1.1.6. Ethnographic-Theoretical Dialogue.

Although I enter the field with specific questions, there must be enough flexibility and reflexivity to allow for adaptation as needed. It is this ongoing interaction between data collection and analysis that Pink and Morgan (2013, 10) describe as the "ethnographic-theoretical dialogue". Although they are different types of activities, data gathering and data analysis are not temporally separate from each other but rather continually feed each other. In their example, Morgan was having difficulty "seeing" a particular aspect of data she was trying to gather – in this case, discussion of occupational safety and health (OSH) knowledge – and Pink encouraged her, citing theoretical concepts from media studies, to look at these knowledge flows in a different way, that is by acknowledging that OSH knowledge was not necessarily discussed in "official" terms but rather through embodied knowledge. In other words, Morgan had no examples of her participants speaking directly to their knowledge of OSH, but she was able to see this knowledge by how

they had embedded certain OSH-related habits into their routines, such as the use of hand gels or latex gloves. This realisation then led to a break-through in how they recognised data sets (Pink and Morgan 2013, 11–12). Rather than waiting until all the data had been gathered and then trying to account for the gaps in it, Pink and Morgan were able to adjust their theoretical lens to immediately and directly address an issue with this adjustment before it became a major problem in their data analysis.

This interaction between data gathering and analysis has also led to an interesting emphasis on practical outcomes of focused ethnographic research. Focused ethnographies are particularly popular in health sector studies (e.g., Wall 2015; Higginbottom et al. 2013; Pink and Morgan 2013; Higginbottom 2008), and these have led to practical changes in the health sector, such as more culturally sensitive nursing techniques in the UK (Higginbottom 2008, 96). As Wall (2015, 12) points out, "there is a drive for research evidence that can be produced in a timely fashion in order to inform policy- and practice-relevant decision making". Higginbottom et al. (2013, 2) even claim that now, "findings are anticipated to have meaningful and useful application". This practicality is especially appealing to me, as I am often frustrated with the disconnect between disability studies theory and application. Focused ethnography provides an opportunity to not simply highlight a problem, but also to potentially enact a solution to this problem.

### 5.1.1.7. Reliance on Audio-visual Data.

As has been mentioned throughout, a shortened time span is a key characteristic of focused ethnography. I have already shown the theoretical implications of this time span, but there is a practical implication as well: data must be collected quickly (Pink and Morgan 2013; Knoblauch 2005). As such, focused ethnography has come to rely on audio-visual means of capturing data. As Knoblauch (2005, 9) explains, the focused ethnographer still relies on observation, but this observation is supported by technologies. The use of tape recorders, video recorders, and cameras has become commonplace, as they allow for rapid data collection (Higginbottom et al. 2013, 5). In a longer, more traditional ethnographic setting, it may not be possible to audio record every encounter, as it would be too time-consuming to transcribe everything or indeed even impossible to store audio files in that quantity. This is perhaps why

focused ethnography is so well-suited to digital methods of capturing data: the shorter, more intense focus means that the moments that are captured are, as discussed above, intentional and deemed important from the outset.

Capturing data digitally also means that they can then later be reviewed multiple times. Pink and Morgan (2013, 12) discuss how they see this reviewing of captured data as "an ongoing form of re-engagement with the materials and context." Although the actual ethnographic experiences can never be fully recreated, they can be revisited through these recordings and re-assessed for deeper meanings. Knoblauch also has an interesting point, that digital records allow multiple people to view the same encounter after the fact and perhaps interpret it differently (2005, 8). Multiple interpretations of a single encounter are still possible with more traditional pen-and-paper field notes, but these digitally-captured encounters are seen through a more detached lens than personal field notes.

That is not to say that digitally captured data are purely detached. As per Knoblauch (2005, 10):

> As many problems as these technologies (and the focus imposed by them) may cause (problems which are widely discussed in visual sociology and visual anthropology), they do change the character of the data produced: one is no longer subject to the "uncurable subjectivity" of field reports but disposes, instead, of a substantial degree of intersubjectivity. This does not mean that recorded data are more objective; it does, however, allow for outsiders to access the data which are less dependent on subjective perspectives than are field-notes.

Recorded data always have an element of subjectivity, as a researcher is required to choose what to record and what not to record, what to focus on and what can be ignored, but they also allow for a fuller experience to be documented. A researcher can then be "in the moment" with their participants, knowing there will be an opportunity to review other aspects of an encounter later.

## 5.2. Focused Ethnography in this Research.

Focused ethnography, as demonstrated above, is defined by more than just its condensed time frame, although that time frame very often shapes other

characteristics of the research process. I have specific, focused encounters with my participants, which are captured using voice recorders and cameras. There are specific questions that are answered, and during my observations, I adapt my theoretical lens to challenges and opportunities as they arise. All of these aspects are explained in further detail below, but focused ethnography has proven itself to suit my research objectives and methods.

I collected data from two main groups of participants: visitors with hidden disabilities and staff/volunteers from heritage organisations. Although I interacted with both groups using focused ethnography, the practical aspects of these ethnographic investigations differed between the groups, as did the goals for each investigation. These differences in approach and outcomes are explained more fully below.

### 5.2.1. Visitors with Hidden Disabilities.

For visitors with hidden disabilities, it was crucial to understand their embodied experience of visiting a museum or heritage site. In order to do this, I followed them through the entirety of a journey, from the preplanning stage, to the visit itself, to a follow-on reflection on the visit as a whole. Further details for each step are below, but all worked together to give me a deeper understanding of how museums and heritage sites can inadvertently exclude people with hidden disabilities and also how these barriers can be dismantled.

### 5.2.1.1. Design.

The research design for my work with visitors with disabilities relies on a series of interactions with participants, including observation and semi-structured interviews in a variety of settings that capture the different stages of a museum visit (i.e., pre-visit research, site visit, post-visit reflection). Following on from Wall's suggestion, I enter these interactions with specific questions in mind (2015, 12). In each section below are a sample of questions; for the full list of questions posed to participants at each interview, see Appendix A.

The target sample size for participants was originally twelve total participants as a way to ensure multivocality in regards to the disabilities represented. With four participants to each site, I believed enough variety between experiences would be

guaranteed, allowing me to find larger themes amongst the data. After putting out a call for volunteers (discussed below in 5.2.1.2) and receiving far more interest than I expected, I increased the number of participants to fifteen: two for the pilot study, one to go to all three case study sites, and twelve who each visit one site, split evenly amongst the three sites. The impact of COVID-19 on this research is outlined more fully in Chapter 7, but because of the pandemic, I was only able to follow ten participants through their full journeys.

Dividing participants this way amongst the sites allowed for a richer data set for me to analyse, and also allowed for a variety of disabilities to be sampled. Ideally, more participants would visit all three sites and thus be able to more directly compare these three sites, but given that the sites are spread across two cities, this would have proven logistically difficult. It would also require a large amount of time on the part of the participants (at least three days for each of the museums), and I felt it was unfair to ask this of all participants. As was discovered, some participants had to interrupt their normal activities and block out extra time to recover should their symptoms increase after a museum visit. However, because I am interested in making direct comparisons between sites, I wanted one participant to visit all three of the case study sites. Because of the pandemic, this did not happen. Additionally, two people were selected for the pilot study to test out the design of the study in order to get feedback on my approach and practice my data collection skills (i.e., think aloud protocols, interviewing, participant observation) before commencing with the other participants.

The sample size has been kept small to allow for a deeper analysis of people's experiences, something which would be hindered with a larger number of participants. Additionally, the number of people with hidden disabilities is large, an estimated 14.1 million in the UK alone (Scope 2021), and the variety of impairments is wide. No two people have the same needs at the same time, and even for one person, their needs may vary from day to day. A person with fibromyalgia may be functionally fine in the morning but by the afternoon, a flare up may have them in so much pain that they cannot move. Hence, I contend that it is more important for this research to look at a smaller number of participants and to comprehensively investigate their accessibility needs than to take a larger sample size and only briefly

glimpse at their varied accessibility needs. Indeed, most research regarding disabled people has a small sample size for this reason (e.g. Lyu 2017; Wan 2015; 2013; Burns et al. 2009).

A small sample size is not without its drawbacks, the most obvious being that it necessarily overlooks some disabilities. In such a large population with such a wide variety of accessibility needs, even amongst people with the same disability, it would be impossible to make a full, comprehensive study of all accessibility needs for people with hidden disabilities. To mitigate this, participants have been chosen to represent as wide a variety of disabilities as possible. Care has been taken to ensure that one particular disability (such as autism or arthritis) does not dominate the data.

Likewise, care has been taken to ensure that the voices of disabled people are amplified through this research. I include direct quotes from the interviews with my participants where I can, bringing their thoughts and experiences to the forefront. Following in the steps of emancipatory research, I draw heavily on the work of Stone and Priestley (1996) and Walmsley (2004) in their discussions of the role of the nondisabled researcher in disability research. Stone and Priestly, in particular, outline a set of guiding principles for nondisabled researchers to follow in order to make sure they are not simply enforcing existing power dynamics and therefore keeping disabled people disempowered by the very research that is meant to highlight their experiences (1996). Although I now consider myself disabled, at the beginning of this research, I did not, and I have therefore embedded these principles into the methodology. They variously include adoption of the social model of disability, emphasising the embodied experience of disabled people, and utilising multiple methods of data collection according to the needs of disabled people (709-10). Of particular interest to me is Stone and Priestly's (1996, 705) statement that "the researcher engages in the process of emancipation, rather than merely monitoring them from sympathetic side-lines." It is not enough for researchers to listen and observe, but they must actively use their research to drive tangible change for their participants. In my research, this takes the form of presenting suggestions and adjustments at my case study sites based on feedback from my participants. To that end, an important step in my research is to present these findings to my case

study sites to encourage them to make these changes. I discuss these suggestions and the responses from the case study sites in Chapters 8, 9, and 10.

Walmsley (2004) builds on Stone and Priestly's work to state more explicitly what the role of the non-disabled researcher should be. Her specific area of research involves people with learning disabilities, which are hidden disabilities and therefore relevant to my research. Her position is that it is sometimes harmful for researchers to surrender their expertise in the name of emancipatory research, casting themselves as mere scribes at the feet of the all-knowing participants (2004, 66). While the participants are experts in the everyday implications of living with a disability, the researcher is still the expert of the process of doing research, and that should not be undervalued (2004, 67). This was a particularly valuable lesson, as during the early stages of this research, I found myself often uneasily taking on the role of "expert" as I developed the methodology. However, as I progressed further as a researcher, it became evident that the particular skills and knowledge that I had acquired and cultivated were invaluable to creating a rigorous piece of academic work. For instance, in my pilot study, I was able to adapt and reword questions in the middle of an interview because I understood the basic point of a particular question. Without my academic skill, the experiences of disabled people would remain isolated anecdotes that would not necessarily drive any amount of change. It is through the partnership of disabled participants and my own expertise as a researcher that these barriers to accessibility are examined and that I make attempts to dismantle them.

Having established my rationale, I now turn to describe the specific approaches I took to gather data from my participants in four contexts: pre-visit interview, site visit, post-visit interview, and follow-up interview.

### 5.1.1.1. Pre-visit Interview.

In this research, data collection begins at the participant's home as this is where a visit truly starts. Accordingly, I arrange a first meeting at each participant's home where I reviewed with them how they plan a visit, from internet research (such as checking a site's website for relevant information) to transport arrangements to planning for what they will take with them on this trip. For many nondisabled people, these steps are quick and almost an after-thought; however, this is rarely the case

for a disabled visitor. Like their nondisabled counterparts (Hernández-Méndez et al. 2015), the vast majority of disabled visitors still use a museum or heritage site's website as their primary source of information (Cock et al. 2018; Euan's Guide 2016). However, in addition to basic information like opening times and admission prices, disabled visitors also require additional access-related information. Wheelchair users, for example, need to know if they can get around a site (Euan's Guide 2016, 4) and blind users want to know if there is information available in alternative formats, such as braille or audio guides (Cock 2016, 7). But these surveys lean heavily towards people with visible disabilities – does the same hold true for visitors with hidden disabilities?

In addition to understanding how they planned for a visit, I also asked my participants to explain the impact of their disability on their daily lives to me. In imparting their embodied knowledge of disability to me, I was able to better understand their perspective throughout our time together. Additionally, I aimed to position them as the "expert" in our interactions, balancing the power dynamics within our interaction (as per Stone and Priestly 1996). Throughout our interactions but especially in this first interview, I emphasised how their knowledge and insight constituted the backbone of my research. Mirroring my initial unease as the role of "expert" researcher, some participants were initially uneasy with the role of disabled expert. I supplied interview questions beforehand, which can be found in Appendix A, as a way to ease this discomfort, showing participants that I was interested not in technical knowledge, but experiential knowledge.

I specifically sought to answer these questions at the pre-visit interview:
- What information do they need to plan a visit?
- What access tools and websites do they use to gain this information?
- How does their disability impact their daily life?

Interviews were recorded and a transcript was produced, which can be found in Appendix C. I also took field notes during these interviews, which can be found in Appendix D. Discussion of the data from the pre-visit interviews can be found in Chapter 6.

The next step was conducting a site visit together. Ideally, I followed participants from their front door to the museum, as physically getting to a place is an important part of a visit and a lack of appropriate transport can hinder some people from visiting in the first place (Euan's Guide 2016). At the museum, the participant led the physical aspect of the visit, guiding where we go within the site, whilst I followed and observed their interactions with the exhibits. The "thinking aloud" protocol (see below) was employed during the site visit to help participants verbalise their experiences and allow me to better collect and interpret their reactions. This protocol also alleviated any pressure from the participants to document their visit, which could not only take away from the normality of the event and therefore skew the data, but also overly complicate things for a participant. An autistic visitor, for example, may find it too stimulating to juggle a museum visit, with all its associated sensory inputs, and also a checklist to document their experiences. These multiple demands on them could not only lead to sensory overload, but also negatively impact the visit, which then further embeds a feeling of hesitancy and anxiousness in potential future visits (Cock 2016; Euan's Guide 2016). There are also learning difficulties, such as dyslexia, which make it difficult for someone to read and/or write, and giving them yet another thing to both read and write about would needlessly complicate their visit and also challenge their enjoyment of the visit. As both autism and dyslexia were hidden disabilities which I was investigating, I did not want to add any extra stress to my participants and therefore decided against administering a participant-written survey. It was better that I as the researcher followed them through their site visit, prompting them with questions as we proceeded and documenting the experience for them.

The Think Aloud protocol was developed specifically to allow researchers to understand a participant's thought process (Fonteyn et al. 1993, 431). Often, participants are asked to perform a task and then talk through their actions as they make them (e.g., Fonteyn et al. 1993), which then allows a researcher to follow the logical progressions of the participant. It is often used in user design evaluations (e.g., Joe et al. 2015; Makri et al. 2011; Jaspers et al. 2004), but has found a home in museum studies as well. Think Aloud protocol was especially helpful in Achiam et

al.'s (2014) study of visitor interactions with museum exhibits. They had visitors interact with particular dioramas within an exhibition, verbalising their thoughts as they did so (468). There was no mentally taxing objective to the task, rather the researchers simply allowed the visitors to explore the diorama as they naturally would but with the addition of thinking aloud. This allowed the researchers to gather qualitative data regarding how visitors use these dioramas, what information they are seeking, and how they negotiate expectations throughout the interaction (2014, 469-71).

I base my use of the think aloud protocols on Achiam et al.'s study: I asked my participants to verbalise their thoughts as they interacted with particular museums and exhibitions. There was no additional mental task, which could lead to sensory overload. Prompting took place in simple phrases like "what are you thinking?" or "keep going" to keep the participant talking.

To familiarise participants with the think aloud protocol and to lessen any awkwardness during the visit, I intended that the participant and I would perform a "warm up" exercise utilising cards with illustrations of different food and drink, as recommended by Ericsson and Simon (1998, 181). First, I demonstrated thinking aloud when dividing up the cards into different piles. For example, I would put cards containing pictures of broccoli, carrots, or lettuce in a "vegetable" pile. I would then place cards with cheese, milk, or butter in a "dairy" pile, and so on. Then, the participant practiced thinking aloud when performing the same task. For example, one participant made a pile of carbs, including cards with pasta, cereal, and bread on them. Then they made another pile of drinks, which included milk, fizzy soda, and water. I encouraged participants to not worry about what piles they created, as the point of the exercise was not to show their sorting prowess, but rather to familiarise themselves with verbalising their thoughts.

I performed this exercise with three participants, but found that although it did encourage participants to verbalise their thoughts and be more at ease in my presence, it was equally as effective to engage in casual conversation with my participants during the pre-visit interview. With one participant in particular, they became distressed as we went through the process, worried that they had

116

misunderstood the exercise as it felt "too easy." Therefore, I stopped using this particular exercise, instead relying on the rapport I built up with participants through our emails and interactions within the initial interview.

I also originally intended to perform an access audit based upon suggestions from my participants. By access audit, I mean methodically exploring a site to catalogue their accessibility tools, such as level floors, lifts, or Braille guides. However, after my pilot study, I dismissed this idea, as I was not interested in an in-depth analysis of a site's accessibility offer, but rather wanted to offer suggestions for improvement. My pilot study participants agreed that a cursory examination of the accessibility provisions at each case study site would be sufficient, particularly as I wanted to understand disabling barriers from the embodied perspective of *my participants* rather than through my own lens.

I specifically sought to answer these questions during the site visit:

- What barriers does the participant encounter?
- How do these barriers affect their visit?
- What things helped their visit?

Site visits were recorded and a transcript was produced, which can be found in Appendix C. I also took field notes during these interviews, which can be found in Appendix D. Discussion of the data from the pre-visit interviews can be found in Chapter 6.

### 5.2.1.1.3. Post-visit interview.

Immediately following the site visit (i.e., on the same day), I conducted a semi-structured interview with the participant. The focus was on our visit together, but I was also open to hearing stories of previous visits to other sites. Hidden disabilities vary in severity on a daily basis, and therefore some accessibility needs may not have been present for our shared visit, hence my desire to hear stories from other visits. It was also possible that a participant had encountered specific barriers during other museum visitors that were not present during our visit, but that had a lasting impact on the participant.

I sought to answer these questions during the post-visit interview:

- What parts of the visit did they find particularly challenging?
- What parts of the visit did they enjoy the most? Why?
- What would they like to tell the museum in regards to accessibility?

This interview was recorded and a transcript produced from it (see Appendix C). As this was an opportunity for the participant to recount their personal experiences and emotions, this interview had a more conversational, relaxed feeling to encourage these personal stories. To aid in creating this mood, the interview took place in a café or tea room near the museum – although two of the case study sites (Treasurer's House and Abbey House Museum) have onsite tea rooms, having a certain amount of physical distance from the museum allowed for a more reflective, open conversation. It also meant that there were no members of museum staff present, which might have pressured a participant into only discussing the positive aspects of the visit.

The interview was recorded and as such, I was not required to take notes in the moment. I therefore could give the participant my undivided attention. Higginbottom et al. (2013, 5), in their discussion of interviews in focused ethnography, stress that the interview should "be started after an informal opening, to put the participant at ease and establish their trust." As the participant and I had immediately come out of a museum visit together, a certain level of ease and trust had already been established. But to ensure that this trust and ease carried on, even in the presence of a voice recorder, I started each conversation off with general questions regarding the visit, such as how the overall visit was, and provided my own answers as well to establish this as a fluid, two-way conversation rather than a rigid and one-sided interview. I had rehearsed my questions ahead of time so that I was able to smoothly interject them into the conversation, rather than making the interview seem like a checklist of questions to be answered (see Appendix A for a full list of the questions).

### 5.2.1.1.4. Follow-up interview.

Between one and seven days after the site visit and original interview, I conducted a follow-up interview with the participant. This semi-structured interview focused more

on other visits, as the participant had more time to reflect on this visit and contrast it with other visits they had done in the past, something I prompted them to consider at the end of our previous interview. It also helped the participant to highlight aspects of our shared visit that since stood out to them as significant and that they may have overlooked in our previous interview. Likewise, it gave me an opportunity to ask follow-up questions to clarify or supplement observations from the visit and interview (e.g., Johnstone et al. 2006, 3).

Research regarding memory creation – and indeed, forgetting as well – shows that there is a bump in recollection one and two days after the initial learning period (Murre and Dros 2015, 19). Likewise, research also shows that after a week, the "forgetting curve" levels off and there is little additional recollection loss (Averell and Heathcote 2011, 32). Because of this, I felt that the best period for a follow-up interview was between these two points, as it gave the participant enough time to sort through all the information they processed during the site visit and to disregard the unimportant moments as well as highlighting the important moments of the visit.

I sought to answer these questions in the follow-up interview:
- How specifically does the participant's disability affect their heritage experiences?
- How did our visit together compare to visits to other museums, especially free-to-enter museums?
- Do they consider themselves disabled?

Like the previous interview, this interview was audio recorded. While the preference was for another face-to-face interview, there was flexibility at this stage for the interview to take place over the phone, as occurred with one participant. Unfortunately, I was unable to conduct this follow-up interview with one of my participants, as they never returned my communications after our visit (see below and Chapter 6 for more information on this and other participants). Appendix C contains the transcripts of these interviews, whilst Appendix D contains my field notes. Appendix E contains my field diaries, in which I reflect on my interviews and site visits with my participants and query themes as I see them arising.

As mentioned previously, careful selection of participants was key to gathering useful data. For the pilot study, two participants, Teagan and Kasi, were chosen based on my previous knowledge of their disabilities – in their case, Ehlers-Danlos Syndrome, ADHD, and dyslexia. For subsequent participants, calls were put out to various disability organisations in Leeds and York, the locations of my case study sites. The University of York Disabled Student Network and Leeds Physical and Sensory Impairment Network were the primary groups used to recruit potential participants, along with the snowball method, where participants were then encouraged to invite friends and acquaintances who might be interested in my research.

Initially, over 20 people volunteered to participate in my research, a number that far exceeded my expectations. I wrote back to each volunteer, inviting them to explain their disability to me, if they were comfortable doing so. Several people never responded, meaning that I could not assess whether they would be appropriate as a participant for my research. Of those that did respond, I created a table of disabilities, dividing responses into three categories: physical disabilities (P), mental health conditions (MH), and neurodiversity (N). I developed these three categories to describe the wide range of impairments that lead to hidden disabilities. In doing so, I was also able to better represent the widest range of hidden disabilities possible through the participants in my research. Table 2 shows the breakdown of the disabilities the volunteers represented and divided into the three categories. Some volunteers are represented anonymously, using a single letter, as they did not become participants and therefore did not sign consent forms in order to share their identity.

| Volunteer | Disabilities | P | MH | N |
|---|---|---|---|---|
| A | Fibromyalgia | X | | |
| Aaron | OCD, autism, bipolar disorder | | X | X |
| Alfie | Dyslexia, monocular vision | X | | X |
| Amanda | Psoriatic arthritis | X | | |
| Amy | Hypermobility, anxiety, OCD | X | X | X |
| B | Anxiety, phobia | | X | |
| C | Myopic dystrophy, learning disabilities* | X | | X |
| D | Concurrent mental health conditions* | | X | |
| E | Dyspraxia, bipolar disorder | | X | X |
| Ellie | Fibromyalgia, chronic vestibular migraines, anxiety, depression | X | X | |
| F | Autism | | | X |
| G | Ulcerative colitis | X | | |
| H | OCD, mental health condition* | | | |
| I | Asperger's, general anxiety disorder, depression, dyspraxia, dysgraphia | | X | X |
| J | Epilepsy | X | | |
| James | Fibromyalgia | X | | |
| Jessica | Dyslexia, Irlen Syndrome | | | X |
| K | Autism, mental health conditions* | | X | X |
| Kasi | ADHD, dyslexia, dyspraxia, EDS | X | | X |
| L | Fibromyalgia, Postural tachycardia syndrome, hypermobility | X | | |
| Lisa | Anxiety | | X | |
| Teagan | Dyslexia, EDS | X | | X |

*Table 2. Volunteers and their respective disabilities divided into categories. *Impairment was never further specified.*

Having created the table, I attempted to select participants that experienced a spectrum of hidden disabilities. Amy (Treasurer's House; anxiety, hypermobility, OCD), for example, had a physical disability, a mental health condition, and was neurodivergent, making her especially important as a contributor to this research. I also attempted to maintain a balance between the three categories to ensure no one type of disability dominated my research. Moreover, I tried to not duplicate

disabilities as best I could, although this proved far more difficult, given the pool of volunteers and their disabilities.

The participants I initially selected and their disabilities are represented in Table 3 below, along with the site I intended them to visit. Again, some potential participants are represented by a single letter, as I was forced to end my data collection prematurely (see Chapter 7), and therefore did not sign consent forms in order for me to identify them in my research.

| Participant | Physical | Mental Health | Neurodiversity | Site |
|---|---|---|---|---|
| A | | Anxiety, Phobia | | Abbey House |
| Aaron | | Bipolar disorder | Autism, OCD | Treasurer's House |
| Alfie | Monocular vision | | Dyslexia | Barley Hall |
| Amanda | Psoriatic arthritis | | | Barley Hall |
| Amy | Hypermobility | Anxiety | OCD | Treasurer's House |
| B | Myopic dystrophy | | Learning disabilities | Barley Hall |
| C | Fibromyalgia | | | Abbey House |
| D | Ulcerative colitis | | ADHD | Barley Hall |
| Ellie | Fibromyalgia, chronic vestibular migraines | Anxiety, depression | | All |
| Kasi | EDS | | ADHD, dyslexia, dyspraxia | Abbey House |
| James | Fibromyalgia | | | Treasurer's House |
| Jessica | | | Dyslexia, Irlen Syndrome | Treasurer's House |
| Lisa | | Anxiety | | Abbey House |
| Teagan | EDS | | Dyslexia | Abbey House |

Table 3. Selected participants and their respective disabilities divided into categories.

As briefly mentioned and further discussed in Chapter 7, the COVID-19 pandemic prevented me from completing data collection, and as such, Table 4 below shows the participants (and their disabilities) that actually took part in my research, as well as the site they visited.

| Participant | Physical | Mental Health | Neurodiversity | Site |
|---|---|---|---|---|
| Aaron | | Bipolar disorder | Autism, OCD | Treasurer's House |
| Alfie | Monocular vision | | Dyslexia | Barley Hall |
| Amanda | Psoriatic arthritis | | | Barley Hall |
| Amy | Hypermobility | Anxiety | OCD | Treasurer's House |
| Ellie | Fibromyalgia, chronic vestibular migraines | Anxiety, depression | | Treasurer's House |
| Kasi | EDS | | ADHD, dyslexia, dyspraxia | Abbey House |
| James | Fibromyalgia | | | Treasurer's House |
| Jessica | | | Dyslexia, Irlen Syndrome | Treasurer's House |
| Lisa | | Anxiety | | Abbey House |
| Teagan | EDS | | Dyslexia | Abbey House |

*Table 4. Actual participants and their respective disabilities divided into categories.*

A brief discussion of each participant and the impact of their disabilities takes place in Chapter 6.

### 5.2.1.3. Data Collection.

Data were collected using several media, depending on the setting and situation. Pen and paper notes were utilised, especially during the pre-visit interview. If

necessary, photos (taken on a mobile phone) were used to document the pre-visit interview, particularly when participants spoke of the accessibility tools they use in their everyday lives.

All interactions were all intended to be audio recorded using a handheld voice recorder and subsequently transcribed (see Appendix C). However, some of my participants were showing distress as we began our site visit. In these instances, to put them more at ease, I decided to not audio record our site visit, and instead took more detailed notes and wrote a more thorough field diary after our visit. During site visits, like the pre-visit interviews, photos were taken to document the visit but also to be used as memory prompts during later conversations (Lin et al. 2016).

For the transcripts of audio recordings, I have employed something called "selective transcription," a method that has been used in a wide variety of settings (e.g., Azevedo et al. 2017; Tian and Zilli 2011; Davidson and Australia 2009; Halcomb and Davidson 2006). Because of the amount of audio recordings, I have only transcribed the parts that are relevant to this research. All audio recordings have been unedited, but due to the amount of work involved in transcribing dozens of hours of audio recordings, as well as concerns around breaching the privacy of my participants, it was most economical to transcribe only relevant conversations. For example, I transcribe my interviews with participants in full so long as we are discussing my research, our visit to the museum, their disability, etc. However, I have not transcribed parts of the interviews where we discuss personal matters, such as someone's dinner choice, or where we were interrupted by non-participants.

During site visits with participants, I have likewise transcribed all relevant conversations. As only the participants have signed consent forms, they are the only ones identified within the transcripts by name. Due to the nature of a museum visit, it was impossible to record only my participant and not any other noise or voices, and this was another consideration in my selective transcription.

Audio was recorded on a handheld voice recorder, then uploaded to Otter.ai for basic transcription. Each transcript was reviewed to select relevant conversations,

then checked for accuracy and edited as needed. Transcripts can be found in Appendix C.

### 5.2.1.4. Ethical Considerations.

Ethics approval was carried out through the University of York. A full ethics form was submitted, as required for research with "vulnerable" groups. According to the university's own definition, this included people with learning disabilities. However, during the process of submitting this form, it seemed somewhat belittling to classify all people with learning disabilities as "vulnerable." Dyslexia, for example, is a neurodivergent condition, often considered a learning disability and affecting a large portion of the population, including several of my participants (Kasi, Teagan, Jessica, and Alfie). None of these participants had any reduced mental capacity due to their learning disability, and indeed, all four hold or are pursuing a Masters degree from the University of York. Alfie has since started a PhD at York as well, while Teagan plans to pursue a PhD in her own right at a later date. It felt demeaning to describe them as vulnerable simply because their brains process letters on a page differently.

The participants were supplied with a copy of the consent form and information sheet via email before our first meeting, giving them time to read over both sheets and ask questions ahead of time. It also allowed them to use a screen reader or other accessibility tool if they wished. A copy of each sheet can be found in Appendix B. At the first face-to-face meeting, physical copies were provided to each of the participants, once again asking if they had any questions or concerns before they signed the sheets and handed them back to me for secure storage.

### 5.2.1.5. Data confidentiality and storage.

As mentioned above, data were captured via audio recording and digitally written field notes, as well as supplementary photos. The audio recordings were immediately taken off the recording device and stored on a personal, password protected laptop, then erased from the device. A backup copy of each recording was also uploaded to a password protected Google Drive folder. The field notes were written via mobile phone into a private Discord server (an application normally used for instant, online communication between people – in this case, I was the only member of the server and therefore only I could see the field notes). Discord's

Privacy Policy prevents the collection of personal data and stores all messages sent on their servers in remote host servers. All field notes were deleted from the server following the transfer to a Google Doc, wiping it from Discord's remote host servers, then copied to a Google Drive document. This drive document was stored in a secure folder that only I and my supervisor could access.

No personal data were gathered aside from that which related to participants' disabilities, and all participants were given the option to use a pseudonym to protect their identity. The signed consent forms were kept in a folder inside a locked filing cabinet, which was itself located in a locked office with key-card access.

### 5.2.2. Organisations.

For my participant organisations, I wanted to understand the culture of their heritage site, particularly attitudes towards accessibility and people with disabilities, as well as how easy or difficult it would be for the organisation to act upon suggestions to increase accessibility.

### 5.2.2.1. Design.

As discussed above, focused ethnography has been chosen due to time constraints, but it also offers the best option for the type of data I wished to gather. At each of the sites, I intended to shadow front of house staff members for a period of four-five weeks, averaging two-three days a week. As discussed in Chapter 7, the COVID-19 pandemic significantly altered these plans, but I was still able to experience an amount of shadowing at each site, observing interactions as well as conducting semi-structured interviews with staff at each site.

Like with my participants, I arrived at each site with particular aspects I wanted to study in mind. These aspects included:
- Language use;
- Underlying attitudes as teased out by interactions and conversation;
- Site-specific accessibility tools.

I was also especially interested in observing any interactions staff may have with visitors with disabilities.

Additionally, I presented the early findings of my research to management-level staff, offering the suggestions that my participants gave. In each of these interviews, I explained the barriers that participants encountered during our site visits, as well as any suggestions they had for improvement. In turn, management staff responded, either with how they would implement these suggestions or the barriers they themselves had to enacting the accessibility suggestions. I discuss these presentations with management staff in Chapter 6, and the questions and comments I posed to them are found in Appendix F, along with field notes from our meetings in Appendix G.

### 5.2.2.2. Sites.

My case study sites have been carefully chosen based on location, the organisations that manage them, and also the fabric of the buildings themselves. All three are listed medieval or early modern buildings, meaning that there are additional considerations that must be accounted for if any significant physical changes are proposed. These additional considerations often make property managers shy away from such changes (as discussed in Chapter 3), normally owing to their cost.

My case study sites are as follows:
- Abbey House Museum in Leeds (run by Leeds City Council);
- Barley Hall in York (run by York Archaeological Trust);
- Treasurer's House in York (run by the National Trust).

Whilst each site is located within a listed building, each organisation represented a different kind of management structure. Leeds City Council is a local council, whilst National Trust is a national charity and York Archaeological Trust is a local charity associated with a commercial archaeology service. I was interested in understanding how the different management structures would respond to accessibility suggestions and, assuming they accepted these suggestions, how able they were to implement them.

As all three case study sites were paid-entry sites, I covered the entrance fees either by previous arrangement with site management (Barley Hall, Treasurer's House) or

by paying for the fee myself (Abbey House). Additionally, consideration was given to location of participants' residents in relation to their particular case study site to reduce transportation costs. Refreshments for any meetings were also paid for by myself.

This financial consideration was important as a means of minimizing barriers to participation in this research. Numerous studies have shown that disabled people have far less financial security (Fremstad 2009; Makaroun et al. 2017; Jorgensen et al. 2018) and I did not want this research, which aims to highlight barriers to participation in heritage, to put unnecessary strain on any potential participants.

For more information on each site, see Chapter 6.

### 5.2.2.3. Data Collection.

Data in relation to the organisations have been collected primarily in the form of field notes, especially as notes on my mobile phone. As mobiles have become ubiquitous in contemporary society, I felt it was less obtrusive for me to do something on my phone rather than making notes on more traditional pen-and-paper (Muskat et al. 2018). It also helped the staff that I shadow feel more relaxed and less like their every word was being scrutinised. Staff self-editing could skew the data and very likely not give me an accurate picture of the culture of the organisation. My notes were later transferred to a word processing document.

As well as in-field notes, I also made daily diary entries after each session. These entries allowed me to reflect on the day's events and to begin processing any important moments that may have occurred. Field notes and diaries can be found in Appendix G.

### 5.2.2.4. Ethical Considerations.

As mentioned, ethics approval was carried out through the University of York and was included in the original ethics approval for participants. Professional participants, as I dubbed them, were provided with an information sheet and a consent form upon my first face-to-face meeting with them. I verbally explained my research to them as

well, then asked if they had any questions before they signed the consent form, which can be found in Appendix B.

Data was captured as digitally written field notes and diaries. As with the data captured from my participants, all field notes were written via mobile phone into a private Discord server, then copied to a Google Drive document. Field diary entries were written directly into a Google Drive document. These drive documents were stored in a secure folder that only I and my supervisor had access to.

No personal data were gathered from the staff members that I shadowed. Signed consent forms were kept in a folder inside a locked filing cabinet that was itself located in a locked office with key-card access.

## 5.3. Data Analysis.

In order to unlock the potential of the data gathered, Critical Discourse Analysis was employed, as I recognised it as the most appropriate theoretical framework to analyse the data. Below is an overview of Critical Discourse Analysis, followed by its application in heritage studies and disability studies, respectively. Finally, I explain its relevance and appropriateness for this research, as well as a brief account of how my analysis proceeded.

### 5.3.1. Critical Discourse Analysis.

> Instead of focusing on purely academic or theoretical problems, it starts from prevailing social problems, and thereby chooses the perspective of those who suffer most, and critically analyses those in power, those who are responsible, and those who have the means and the opportunity to solve such problems now (van Dijk 1986, 4).

The above is how Teun van Dijk describes Critical Discourse Analysis (CDA herein) and positions it as different from other linguistic and social theories. At its most basic, CDA looks at the language used by those in power to keep others oppressed, then offers insights on how to challenge these structures. As a critical linguistic theory, it acknowledges that language shapes thought and action (Janks 1997), which in turn

shapes power dynamics. However, it is not enough to simply identify how the linguistic structures reinforce inequality. A further step must be taken, wherein scholars must actively challenge these dynamics – they must use these insights to "challenge power, to subvert it, to alter distributions of power in the short and long term" (Wodak 2011, 52-53). The idea of challenging and subverting structural inequity perfectly aligns with my own views of research: it is not enough for me to show how difficult it is for visitors with hidden disabilities to fully engage at museums and heritage sites, I must expose the barriers they encounter and offer concrete solutions to dismantling these barriers. Sometimes, this comes through the introduction of new accessibility offers at a site. Sometimes, this comes through completely rewriting the accessibility policy of an organisation.

### 5.3.1.1. CDA and Heritage.

In the field of heritage, CDA has been used surprisingly little to analyse current practices in the field. One significant exception is the work of Waterton et al. (2006), who used CDA to analyse the Burra Charter. The Charter is a policy document which outlines best practices in Australia heritage management and conservation, and has been influential in the creation of similar charters (Qian 2007). By closely reading the Charter and applying CDA techniques, they reveal that although subsequent additions and amendments to the Charter have aimed to make it more inclusive, "the discursive construction of the Burra Charter effectively undermines these innovations" (Waterton et al. 2006, 351). For example, the 1999 revisions to the Charter sought to incorporate "new ideas" and allow for "the co-existence of cultural values, where they conflict" (Australia ICOMOS 2000, 22). However, this aim was significantly undermined by the authoritative tone of the entire document. As Waterton et al. (2006, 347) put it, "overall, the text reads more as a series of categorical statements that signal authority and expertise in an explicitly unidirectional flow of information, with a seriously diminished dialogicality of text." In other words, the Charter positions itself as the ultimate authority on heritage and conservation, sharing its expertise with less-informed individuals and organisations. This necessarily means that any opposition to the Charter's position or views is inherently wrong, or at least ill-informed and therefore can be disregarded. This close attention to the language and construction of the Charter shows how difficult it can be to enact effective change, despite earnest attempts to do so. Until the language of

the Charter as a whole is transformed, it cannot be the tool for wider inclusion as has been the aim of later iterations.

As can be seen from the above example, CDA provides an excellent framework to uncover the subtle ways that heritage policy reinforces barriers and exclusionary practices, despite claiming to do otherwise. It is hoped that future work will be done in this same vein, using CDA techniques to critique and revise current and future policies. For now, however, it has proven itself as a valuable resource that provides the basis for the analytical work done in this research, as discussed below.

### 5.3.1.2. CDA and Disability Studies.

Perhaps even more surprisingly, there has been little interaction between CDA and disability studies. In a field where the ontological implications of "people with disabilities" versus "disabled people" have never truly been settled, CDA seems a natural fit for such discussions. And yet, only a handful of scholastic articles combine the two in any depth.

One such article is an analysis of the disability policy documents used by a Norwegian NGO – Norwegian Federation of Organisations of Disabled People (FFO hereafter) – which represents a wide variety of disability organisations (Grue 2009). Grue systematically codes these documents to understand the underlying assumptions of disability and accessibility that FFO acts upon. Through this close intertextual analysis, he shows that there is no explicit model of disability that the organisation espouses, but rather a fluid understanding that disability can be socially constructed but also an inherent condition of a person (2009, 306). For example, one of the FFO documents reads: "To exclude people with disabilities and chronic illnesses by inflicting on them additional expenses which are caused by consequences of the disability or chronic illness, is also a form of systematic discrimination" (as quoted in Grue 2009, 322). This is a perfect blending of both the social model and the medical model of disability. On one hand, the person is being disabled by a society that forces additional expenses on them in the management of their condition, thus following a social model wherein society is the disabling factor. However, it also incorporates a medical model view, in that the disability or chronic illness is a property of the individual, and something that must be managed and

accounted for. By orienting disability as something that can be both socially constructed and medically inherent, they bridge the gap in what could be (and indeed has been, especially within the scholarship) an acrimonious debate. Most importantly, it is through CDA that this understanding of disability is elucidated, as nowhere it is explicitly stated in FFO's policy documents. By using CDA techniques, a hybrid model of disability can be articulated in ways that have been impossible until now.

### 5.3.2. CDA and this Research.

As mentioned above, CDA is a particularly useful theoretical structure for uncovering the subtler power dynamics at work in accessibility. It should be noted that CDA is particularly relevant for the data that come from my case study organisations, as these sites are in a position of power with the ability to enable or deny disabled visitors. All my case study organisations have expressed a genuine desire to increase their accessibility, but CDA can help to reveal the likely organisational commitment to these desires.

In order to undertake this analysis, these sites are in a position and coded different interactions between disabling barriers and my participants. Because I engaged in focused ethnography, the ethnographic-theoretical dialogue (as per Pink and Morgan 2013) allowed me to reflect upon emerging trends in the data set and then ask further questions of my participants to clarify and solidify – or adjust – these trends.

As my data collection progressed, I returned to this method continually. Initially, I was concerned with uncovering the disabling barriers faced by my participants, but as I moved into analysing the site organisations themselves, I particularly applied CDA to examine the power dynamics involved. These power dynamics are discussed more fully in Chapter 8, but suffice to say that I found CDA particularly helpful to understand the subtler aspects of disabling barriers.

Additionally, an important aspect of CDA is challenging oppressive power structures, which I considered a mandate of my own research too. To that end, I conducted interviews with management staff at case study organisations, presenting them with the disabling barriers encountered by my participants, as well as their solutions

where appropriate. With permission from my participants, I explained not only what these barriers were, but also why they were particularly disabling, allowing management staff to better understand the embodied knowledge of my participants. Using my position as a doctoral research student, a position which lent me an amount of academic authority and credibility, I challenged the organisations on their decisions, asking them to explain unintentionally disabling policies and actions and guiding them to more inclusive approaches. I outline these interactions in Chapter 6, and discuss them further in Chapters 8 and 9.

## 5.4. Summary.

Throughout this chapter, I have outlined the various steps I undertook at each stage of my data gathering and analysis. By using the techniques and concepts embedded in focused ethnography, I have been able to gather the experiences of people with hidden disabilities when visiting a museum or heritage site in their entirety. Through a combination of participant observation and semi-structured interviews, I gained insight into the barriers they faced as well as potential solutions to dismantle these barriers. With my case study sites, I use a combination of participant observation and semi-structured interviews, particularly grounded in Critical Discourse Analysis, to uncover the systemic hurdles that may prevent meaningful change taking place.

All of this is done with the aim to generate ideas and solutions to disabling barriers across the heritage sector. A final, crucial step is to implement some changes at the case study sites to determine their feasibility and their efficacy. As highlighted in CDA and disability studies more generally, I cannot in good conscience stop at merely identifying the problems: I must use my own position and authority to push for change where I am able, which I discuss throughout Chapters 8-10.

In the next chapter, I outline the main data that I collected, both from participants and from case study organisations, in line with this methodology.

# Chapter 6 – Data.

Having discussed my methodology in the previous chapter, I now turn to the data I collected. I have organised it similarly to Chapter 5, dividing this chapter into two halves: data from participants and data from organisations. However, I discuss the organisation data first, as it is necessary to explain the setting in which my participants make their comments. To that end, I describe each case study site, including their accessibility offer. I also describe the interviews I conducted with staff members, both front of house staff and management staff. I then turn to participant-centred data, briefly describing each participant, as well as the journey that I took with them through each site.

## 6.1. Organisation-centred Data.

In this section, I describe my case study sites and the organisations that manage them. I discuss the accessibility offers at each site with particular emphasis on the accessibility provisions for visitors with hidden disabilities prior to my research. I also describe the interviews I conducted with staff members firstly as I shadowed front of house staff members, and then again later when I presented my research findings to management staff. I list the case study sites alphabetically, as I was constantly in contact with each site throughout my research and there was little chronological order to them.

Please note that, in line with the recommendation of the University of York Ethics Committee, I have assigned pseudonyms to all staff members. I have also strived to keep their job title as vague as possible to avoid revealing their identities and provide full anonymity. Additionally, all material contained in this thesis complies with the Ethics Committee standards. Staff and volunteers were aware of my presence at all times, and I was an active participant in their conversations. At no time did I record or take notes on private conversations.

### 6.1.1 Abbey House Museum – Leeds City Council.

Abbey House Museum in Leeds is housed within a Grade II* listed building, originally the gatehouse of nearby Kirkstall Abbey. Today, it houses a collection dedicated to

social history and childhood experiences in Victorian-era Leeds (Leeds Museums and Galleries 2021d). The ground floor has a recreated Victorian Street that visitors can wander through, as well as a free-to-enter café. The first floor has the "gallery of childhood" that holds a large collection of Victorian toys and games, explaining the everyday life of a child in Victorian times. It also has a soft play area for smaller children and a temporary exhibition space. During my visits with my participants, the temporary exhibition on view at the time was titled "Danger Zone," exploring the hidden dangers that lurk in common, everyday objects from the past 200 years (Leeds Museums and Galleries 2020b). During my shadowing experience, it had been replaced with "Sounds of Our City," an exploration of music styles and their development within Leeds (Leeds Museums and Galleries 2021e), although it had an almost identical style and format.

Abbey House is managed by Leeds City Council as part of their Leeds Museums & Galleries (LMG) portfolio, which includes nine different cultural sites around the city. LMG represents the largest local authority-run museum service in the UK, and is celebrating its 200th birthday in 2021 (Leeds Museums and Galleries 2021c). I specifically chose LMG to understand the multiple levels of approval that proposals must be put through in order to enact change. Given the organisational structure of LMG, I wanted to understand how the bureaucracy involved in local councils impacted accessibility proposals at a site like Abbey House.

According to their website (Leeds Museums and Galleries 2021f), Abbey House provides the following accessibility measures:

- Level entrance from the street;
- Lift to first floor;
- Wheelchair available to borrow;
- Guide and assistance animals welcome, including a water bowl for their use;
- Accessible parking bays on-site;
- Accessible toilet;
- Braille interpretation material;
- Audio elements;

- Handling sessions and touch tours available upon request (two weeks prior to visiting).

On their website, their access provisions are listed by disability categories (Leeds Museums and Galleries 2021f), a system that is strongly discouraged as being confusing and potentially discriminatory (Fisher 2017). Additionally, none of the categories include hidden disabilities. Arguably, many of these accessibility tools can be utilised by visitors with hidden disabilities, such as the accessible toilet or the wheelchair, but as no hidden disabilities are listed in the category, they imply that visitors with hidden disabilities are not necessarily welcome to use these tools.

### 6.1.1.1. Data Collection – Front of House.

I spent one day shadowing front of house staff at Abbey House, although I had originally intended to spend at least ten days here. Despite this, my experience during that day aligned with the experiences of my participants when we visited previously as well as what managerial staff expressed, so I do not believe I failed to take account of anything significant.

The front of house staff members I interviewed were:
- Ian;
- Ella;
- Danni;
- Tim.

When I first arrived at Abbey House in June 2021, I was warmly greeted by two male staff members in the admissions/shop area and explained why I was there. They had been told to expect me, and invited me to head into the museum while they let the duty manager know I was there. Although the two staff members in the admissions/shop area knew who I was, the staff members I encountered in the rest of the museum did not initially know I was there as a researcher and visitor. I spent some time touring the museum as if I was a visitor, reacquainting myself with the site after a pandemic-related absence of over a year. I also took this opportunity to see how the museum had adjusted to a COVID-19 world, which I discuss in Chapter 7. Having already done much of my participant data analysis, I was both pleased and

dismayed to see some of the changes, and made notes in my phone and took photos to document these changes and my initial thoughts.

After I toured the museum, I returned back to the admissions/shop area and was greeted by the duty manager. He asked if there was anything else that I needed, to which I said no, and replied that if I needed anything, to let one of the front of house staff members know, and they would either help me themselves or radio him if it required his attention. Following that, I interviewed four front of house staff members, asking questions that I had developed during my time shadowing at Treasurer's House (for a full list of these questions, see Appendix F). All four staff members were incredibly kind and helpful, even excited to participate in my research. They all expressed a desire to increase the accessibility of Abbey House, acknowledging that physically, there was little they could do to alter anything. However, they were eager to hear any suggestions that they could implement, especially once I explained that the suggestions I had came from my participants.

While I was shadowing, a visibly disabled visitor, whom I have named Adam for sake of ease, arrived. Adam had a learning disability, although I did not inquire as to the exact nature, as I was more interested in how the staff members reacted to them. Admittedly, the staff members were aware I was observing them, but I did not notice any of the staff members treating Adam differently from a nondisabled visitor. They greeted Adam with the same enthusiasm and patience with which they had greeted all other visitors, addressing Adam directly when answering a question instead of Adam's companion, a practice that is frowned upon but far too common (Nario-Redmond et al. 2019). I did not follow Adam and their companion through the museum, but I did notice them again as they left the museum. Both looked relaxed and content, which I interpreted as a positive museum experience.

### 6.1.1.2. Data Collection – Management.

I was in direct contact with a senior management member at Abbey House, Mary. We primarily communicated via email, although I was able to arrange an in-person meeting with her as well as a virtual meeting with her over Zoom once COVID-19 became a concern.

When I first contacted Mary in March 2018 about including Abbey House as one of my case study sites, she was enthusiastic about the arrangement. Her only concern was that participants would expect far more than she was able to deliver – in particular, she mentioned that they would be unable to install a Changing Places toilet, a common request that unfortunately, Abbey House does not have the space to accommodate. A Changing Places toilet is seen as the most accessible toilet, as it includes hoists and larger changing tables to aid in lifting adults from wheelchairs to change their incontinence pads or pants, something that is almost impossible even in accessible toilets (Changing Places 2021). However, Changing Places toilets also require a larger footprint than other toilets, and buildings such as Abbey House simply do not have a suitable space to place such a toilet. Once I had assured her that I would inform participants that, although I would pass their suggestions to my case study sites, there was no guarantee that these suggestions would be implemented, she immediately agreed to take part in my research.

I stayed in contact with Mary through email for the majority of my research, keeping her informed of different milestones as I accomplished them, such as when I received ethics approval and when I would begin bringing participants to her site. At every step, she was encouraging and kind, excited to hear developments as they occurred. She also helpfully answered questions I had about the museum itself, clarifying the roles and responsibilities of particular staff members as well as explaining the thought process behind specific policy decisions.

In July 2021, I connected with Mary again over Zoom to present to her the findings of my research. I discuss this meeting more thoroughly in Chapters 8-10, but she enthusiastically accepted the suggestions, explaining that they aligned with a lot of what they had hoped to accomplish at Abbey House, and noting that with my research in hand to show to the Council, they were far more likely to receive approval for some of these changes.

### 6.1.2. Barley Hall – York Archaeological Trust.

Barley Hall is a grade II listed medieval house in York city centre (Historic England 2021a). It was purchased and restored by York Archaeological Trust in the 1980s, and now acts as an interactive museum about York in Tudor times. The museum

situates itself as an interpretation of what Barley Hall was like around 1483, when it was owned by York goldsmith William Snawsell (The JORVIK Group 2021) – even if the name "Barley Hall" is a 20th century invention. Documentary and archaeological evidence related directly to the site has been utilised throughout the museum, including original medieval elements, such as timbers, where possible (York Archaeological Trust 2011, 12). On the ground floor, each room has been designed to represent its use during the 15th century, such as a steward's room, a Great Hall, and a pantry. Replica objects are placed where they would naturally have been, such as cups and bowls on tables in the Great Hall. This not only enhances the "authentic" feel of the museum, but also encourages visitors to interact with the items, creating a more immersive environment. Additionally, a temporary exhibition called "Magic and Mystery," examining the intersection of magic, religion, and science in the medieval mindset, was in place during not only my participant visits but also my ethnographic observations.

YAT was founded in 1976 as an independent charity with the aim of investigating "the past for the benefit of present communities and future generations" (York Archaeological Trust 2021). It is headed by a Board of Trustees and has two main branches: the commercial archaeology branch (York Archaeology) and the attractions and events branch (the JORVIK Group). In 2019, when my research began, the JORVIK Group operated five attractions: the JORVIK Viking Centre, DIG, the Richard III Experience, the Henry VII Experience, and Barley Hall. Unfortunately, due to COVID-19, the Richard III Experience and the Henry VII Experience were closed with plans to re-open them in some form in the future; however, neither have fully re-opened as of the writing of this thesis. I chose YAT to understand the complexities of a local charity that does not have a steady source of external income and instead relies on grants and income from admissions at their attractions.

It should be noted that during the course of my research, I was employed by YAT and sat on the Access Team for the JORVIK Group. I produced the accessibility guides for all attractions, including Barley Hall, since best practice for accessibility guides was the subject of my Master's dissertation (Fisher 2017). I was primarily based at DIG, although I did work occasional shifts at Barley Hall before commencing my research. My pre-existing link to both Barley Hall and YAT had the

potential to colour my perceptions of this particular case study site, as I could either be too lenient or too harsh in my analysis. However, I put several measures into place before beginning my research to ensure I maintained a level of detachment: I was not given shifts at Barley Hall, nor did I intentionally interact with Barley Hall staff members, both front of house and management, in a professional capacity. Although some of the staff members I interviewed were well acquainted with me, we maintained the same level of professionalism that I experienced with the other case study organisations.

Additionally, my experience working for YAT meant that I had a way of embedding myself into other organisations more easily. I could offer my own experiences as a front of house or management staff member, encouraging my interviewees to share their own experiences in turn. As with all interactions, I was careful to ensure that whatever comments I shared were delivered in a fashion that was as neutral as possible so a staff member would not self-edit their own experiences but rather explain their own embodied knowledge of their site. Ultimately, I found that sharing my experiences engendered an automatic level of trust in most of my interviewees, enabling me to act as "both outsider and insider" (as per Wall 2015, discussed in Chapter 5).

Barley Hall is rather notorious amongst staff for its lack of physical access, as there is no lift, no level access to the site, and no level access within the building itself, with raised thresholds impeding access in many areas, shown in Figure 4.

*Figure 4. Tall thresholds in the doorways to each room prohibit level access throughout Barley Hall.*

According to their website (The JORVIK Group 2021a), Barley Hall provides the following accessibility measures:

- Braille and large print guides;
- Foreign language guides;
- Guide and assistance animals welcome, including a water bowl for their use;
- Automatic subtitles on videos;
- Seating available throughout the museum;
- "Traffic light" sticker system, signalling a visitor's preferred level of engagement from staff members;
- Sensory packs;
- Portable ramps for thresholds;
- Visual stories.

Although not advertised as an accessibility measure, Barley Hall offers multi-sensory interpretation. Alongside traditional text panels are tactile and aromatic aspects, such as samples of flowers and herbs for visitors to touch and smell. This multi-sensory approach to museum interpretation, often lauded as best practice in general (Levent and Pascual-Leone 2014), is particularly appropriate for people with disabilities – no one sense is primarily used, which would then put someone at a disadvantage if that particular sense is impaired (Davidson et al. 1991).

### 6.1.2.1. Data Collection – Front of House.

As with Abbey House, I was not able to shadow as many days as I had originally intended. Again, like Abbey House, I spent one day shadowing front of house staff and again, my experience that day only complemented what I had seen during visits with my participants. I interviewed two staff members during my time there.

The front of house staff members I interviewed were:

- George;
- Gwen.

In July 2021, I arrived at a much-changed Barley Hall. The changes are detailed in Chapter 6, but to summarise in brief: the layout of the museum had been altered, the number of staff members had increased, interactive elements had been removed, and maps of the site had been introduced. Because the experience itself had changed from what my participants experienced, I focused solely on the staff experience in my interviews and observations.

I stationed myself near the admissions desk to interview George and Gwen, the two front of house staff members working that day. During my interviews, there were numerous interruptions so that they could attend to visitors, something I gladly stepped aside to watch. Although no visibly disabled visitors attended on the day I was there, both George and Gwen shared stories with me about their interactions with disabled visitors. George admitted that he did not have many shifts at Barley Hall prior to COVID-19, as he usually worked at one of the attractions that has since closed. Gwen, on the other hand, preferred Barley Hall to all the other attractions within the JORVIK Group.

We were also joined multiple times throughout the day by one of two managers. They did not linger or hover, as they were performing their "checks" – an hourly walk-around of the site to check the toilets and ensure there was nothing amiss in the museum. However, both managers stopped and chatted genially with the front of house staff members, asking how they were or if they needed a break and also if everything was fine in the museum itself. Despite how brief these encounters were, there was clearly a good rapport between the managers and front of house as well as a sense of respect in each other's abilities. Gwen confirmed this, saying "it's nice that they trust us to get on with the job" (Appendix G 2.1).

### 6.1.2.2. Data Collection – Management.

My main contact in the organisation was Maggie, a senior manager for the JORVIK Group. She also sits on the Access Committee and we had worked together previously on other accessibility-related projects, as I mention in 6.1.2. above. We communicated primarily through email, and I was able to conduct a face-to-face interview with her in July 2021 to present my research to her.

During our interview, Maggie was very excited to hear the suggestions of my participants. Particularly regarding the new map, she said that there was debate amongst the senior management team as to whether they should continue to offer it, but with the support of my research, she was confident she could convince the team to keep the maps, along with the adjustments that Teagan suggested (see below in 6.2.10). She agreed that the lighting at Barley Hall was a problem, as expressed by multiple participants (e.g., see Chapter 8) and they had been searching for a suitable solution for some time now. She also quite liked Amanda's suggestion for rope holds in the doorways to help people over the thresholds (see 6.2.4.2 below). She indicated she would speak to the technical team, who is in charge of many practical matters at the sites, and see if they had a solution.

Given her position within the management structure of the JORVIK Group and on the Access Committee, she had the ability to implement larger accessibility suggestions, such as the personal interpretation boards. Indeed, she made a note to speak to

members of the interpretation team and the head of travelling exhibitions about incorporating these boards into all exhibitions with the JORVIK Group.

### 6.1.3. Treasurer's House – National Trust.

Treasurer's House is a Grade I listed (Historic England 2021b), although its architectural history is complex. A 17th century rebuild of a 16th century house, a considerable renovation of the building in the late 19th century brought the house into the space it inhabits today. In 1930, Frank Green, the last owner of the with house, gifted the property to the National Trust with the promise they would maintain the house in the way he had styled it (National Trust 2021d). To this day, the Trust still preserves the house as Green left it, down to the brass tacks he installed to make sure that his furniture was not moved around

Founded in 1895, the National Trust is well-known as a national charity that owns and manages a wide variety of properties, from castles and historic houses to nature reserves and gardens (National Trust 2021e). Headed by a Board of Trustees, the National Trust has a policy of "for ever, for everyone" that guides all their management and conservation decisions. I chose National Trust in order to examine an organisation that embodies both a local authority council and a local charity: although National Trust is far from local, they have an organisational structure that is similar to a council yet they must also work within the financial constraints of a charity, with no external income streams.

Interestingly, during the course of my research, National Trust changed their policy to "for everyone, for ever" (National Trust 2021e), reflecting a greater emphasis on visitors rather than the collection. I discuss the implications of this change in Chapter 10.

Like Barley Hall, Treasurer's House acknowledges that the physical access of the site is not ideal, as it includes many stairs throughout the building but no lift or ramps. However, according to their website (National Trust 2021b), Treasurer's House provides the following accessibility measures:
- Guide and assistance animals welcome, including a water bowl for their use;

- Large print, hard of hearing, and non-accessible route transcripts of the guided tour;
- Accessible toilet;
- Seating available throughout the property;
- Induction hearing loop.

Unlike Abbey House and Barley Hall, Treasurer's House does not list these measures by disability category, but rather by where these accessibility measures are located, as is considered best practice (Fisher 2017). Treasurer's House also lists additional information, such as door widths and number of steps in a flight of stairs. The addition of these details allows visitors to decide whether an area is suitably accessible for them, which is also considered best practice and is particularly helpful for people with hidden disabilities who may experience uneven impairments throughout their day (2017, 85).

### 6.1.3.1. Data Collection – Front of House.

Unlike Abbey House and Barley Hall, I was able to spend five days shadowing front of house staff at Treasurer's House. I had originally intended to spend an additional five days shadowing after they reopened following their usual winter closure, but the COVID-19 pandemic occurred during that closure, forcing me to alter those plans. However, as with Abbey House and Barley Hall, the time I spent shadowing complemented what I had seen during my visits with participants. I was able to interview five front of house staff members and observe two volunteer room guides during my time at Treasurer's House.

The front of house staff members I interviewed were:
- Thomas;
- Jamie;
- Jay;
- Issy;
- Lee;

Additionally, the volunteers I interviewed were:
- Sophie;

- Caitlin;
- Michael;
- Carly.

I began my shadowing experience in December 2019 with Christmas at Treasurer's House in full swing. Staff were allowed to wear Christmas jumpers, something they whole-heartedly embraced. The property was decorated for the season, with wrapped boxes and decorated trees in nearly every room. The decorations had been a point of contention amongst my participants – a long garland of greenery was wrapped around the banister of the main staircase. As will be discussed Chapter 10, this simple decoration had a lasting impact on many visitors.

There were also some complaints from staff members about the ticketing system for Santa's Grotto, a meet-and-greet with Santa event that is popular every winter season at the property. Repeatedly, they challenged their inability to adjust bookings on the day, particularly when visitors did not show -up for their time slot. Indeed, all tickets had to be pre-booked at least a day in advance, an uncommon requirement for Treasurer's House before COVID-19. There was a sense that the front of house staff had been disempowered, that they were no longer trusted to do their job. Multiple times, they had to turn away disappointed children, parents, and grandparents, saying they could not sell any tickets, despite knowing there were spaces available. Amongst themselves, they discussed their frustration over the procedure, but when I questioned if they had spoken to their managers about this, seeking clarity on this policy or asking for adjustments to it, the general consensus was that there was no point in asking. "It took us months of asking to even get a desk lamp so we could see what we were doing," one front of house staff member commented.

Indeed, the lighting is something that I had noticed almost immediately about the reception area. I was shadowing during the winter season, when daylight is scarce in Northern England, and Treasurer's House had proven to have low lighting levels according to my participants. In the reception area, these low lighting levels were particularly apparent, especially as its location meant it had little natural light. Due to

conservation concerns, ecological policies, and even National Trust's promise to Frank Green to not change anything, Treasurer's House insisted that any electric lighting needed to be subdued. However, in a room where employees were required to read and write as a significant part of their job, I was taken aback at the fact a simple desk lamp, one that could be set aside and nearly hidden on the desk, had been so controversial with management.

Despite these grievances, front of house staff clearly enjoyed their job and their co-workers. There was a great sense of friendliness between reception staff, and they quickly welcomed me into the fold. Several times, when there were no visitors in the reception area, they updated each other on their personal lives and were clearly at ease in one another's presence. I asked them if they spent time together outside of work, and several staff members said they did not, as many (if not most) of them worked a second job and thus had limited free time. However, many of them expressed interest in participating in more "team building" exercises, as they did enjoy each other's company.

It became clear, however, that this friendliness did not extend across everyone within Treasurer's House. There were no apparent rivalries between any particular groups, but it was obvious that there were multiple groups of employees, and each kept to their own group. Amongst the paid staff, groups included the reception staff, the café/shop staff, and the management staff. Only once did I see any interaction between these three groups, when a manager was at the reception desk waiting for one of the National Trust's staff photographers. She spoke genially with the reception staff, but as soon as the photographer arrived, she left and was not seen again that day. I never saw any interaction between reception staff and café/shop staff, although this may be partly due to the locations of each area.

Even amongst the volunteers, there were strong divisions between groups. One volunteer commented that groups were based on which day a volunteer was on site. Within these groups, there were strong friendships, and these volunteers did spend time together outside of their Treasurer's House shifts, but it could be difficult to "get in" the group as an outsider. Again, this is only one volunteer's perspective, but a front of house staff member did comment that they did not recognise all volunteers

when they arrived for a shift, and relied on the volunteer's apparent level of comfort at the property to determine if they should be allowed into the volunteers' break room. Security concerns aside, it is clear that there is little if any contact between different groups at Treasurer's House.

Despite these internal conflicts, it was abundantly clear to me that front of house staff at Treasurer's House were committed to providing the best possible experience for visitors, particularly disabled visitors. All five staff members I interviewed were well-versed in the site's accessibility (and its weaknesses) and were eager to share stories of their interactions with visibly disabled visitors. During my time onsite, I observed them interacting with several disable visitors, including visitors with mobility difficulties and visitors with learning difficulties. In all these interactions, they showed the same professionalism and enthusiasm that they showed to all other visitors, making sure to highlight potential barriers (such as number of steps in a staircase) as well as potential aids (such as seating in each room). Additionally, when I arrived for my second day of shadowing, both reception staff excitedly told me about a visitor who had a guide dog that had been on site the day before. Their enthusiasm for and knowledge of accessibility greatly impressed me.

### 6.1.3.2. Data Collection – Management.

My primary contacts at Treasurer's House were and Diane, both senior management staff directly responsible for Treasurer's House. Most of our communication was done via email, but I did conduct an interview with Ellen when I had concluded the site visits with my participants. In addition to the emerging trends I had noticed by that point in my research, there were site-specific aspects of my research that I shared with her. A fuller discussion of these barriers is included in Chapters 8-10, but at this meeting, I pointed out in particular the low light levels, the lack of seating around the property, and the banister issue I mentioned above in 6.1.3.1. I also provided her with a list of these points prior to our meeting so that she could prepare her responses. During our interview, she expressed very little surprise that the light and the seats were mentioned, saying that these have been ongoing complaints. However, she offered no alternatives for them, citing guidelines for textile conservation as a reason for the low light levels and also pointed out that there is seating available within each room, although participants specifically said that they

could not differentiate between chairs they could sit in and chairs they could not. She also clarified some confusion that I had regarding the training that staff and volunteers receive as part of their induction, as well as the general structure of management within Treasurer's House. Ellen also shared with me some future plans for the property, including the introduction of a pamphlet which would include a map of the property and tablets for room guides that contained additional images and information to show to visitors.

I communicated with Diane solely through email, where she was mostly arranging the logistics of my visits and also introducing me to relevant staff members at Treasurer's House. Both Ellen and Diane were eager to implement any suggestions that they were able to, so long as it did not go against National Trust policies or if they needed to be approved by regional or national managers.

Additionally, I did conduct a brief interview with Alice, the Volunteers Manager at Treasurer's House. I queried her regarding the garland on the banister, and she confirmed that it had been changed. A room guide had noticed a visitor having difficulty navigating the stairs because of the garland, so the room guide passed the observation along to Alice, who corrected the placement. Interestingly, she also revealed that in the original design of the decorations, the garland was supposed to hang specifically so that it did not interfere with visitors' ability to use the banister. However, this intention was not communicated clearly to the volunteers who installed the decorations, hence the problem with the garland.

Unfortunately, I was unable to contact anyone at Treasurer's House after COVID-19 and therefore have not been able to present my research to the management staff at the property. However, Dr Heather Smith, Equity Officer for National Trust, sat on my Thesis Advisory Panel and, through personal conversations, I was able to ask her for clarification about the management structure of National Trust, amongst other things (see Appendix F for full list). I have shared my research with her and although she could not attest to any changes that would be made specifically at Treasurer's House, there was interest in embedding some of the points in Chapters 8-10 across National Trust as a whole.

## 6.2. Participant-centred Data.

In this section, I describe my participants and their disabilities. I also provide narrations of our interactions as outlined in Chapter 5 with particular emphasis on the disabling barriers they encounter. I list the pilot study participants first, as their input greatly influenced the structure and nature of my research. After that, I list participants alphabetically rather than chronologically, as I was often scheduling several participants within one week. I describe their disabilities, using quotes from participants themselves. I also detail our interviews and site visit, as outlined in Chapter 5, and utilise quotes from participants and details from my own field notes and field diaries. Transcripts of these interviews can be found in Appendix C whilst my field notes can be found in Appendix D and my field diaries in Appendix E.

## A note on format.

In Chapter 1 and throughout the rest of the thesis, I utilise a narrative approach to the data, as I deemed it the most appropriate way to explore the words, actions, and nuances of each interaction rather than a flat presentation of facts. Vignettes are a widely recognised tool in ethnographic studies as a means to convey the intricacies of an interpersonal moment. Although they are constructed as narratives, they are based on field notes and transcripts (Jacobsen 2014, 38) to provide a level of authenticity. The details that are added by the ethnographer are meant to bring a reader into the moment, to experience the interaction as the ethnographer did (Humphreys 2005, 842). Vignettes offer a perspective that other methods of writing do not offer, and when trying to explain the experience of disabled people, I find vignettes incredibly impactful.

Vignettes have been used to great effect in studies with disabled people. For example, Winder-Patel et al. (2021) studied levels of anxiety in autistic children. Their research necessitated a flexible approach to how they conducted interviews, and they present their data collection process in a series of vignettes (2021, 8-11). The vignettes allow the authors to describe not only the words and actions of their participants, but also to explore the cause of these behaviours. For example, they write (2021, 8):

> When Kylo was around people, he would talk repetitively to his parents in a
> pressured way about his favourite food, which was French fries, even if he had just
> eaten. He appeared comforted by thinking about this preferred food like another child
> might be comforted by a favourite object, such as a blanket.

The added context, detail, and intuitiveness of the vignette more fully describes Kylo's behaviour. Merely explaining that he repeatedly talked about French fries would not provide a full picture of the encounter. Likewise, I believe that the additional narrative elements of vignettes provide a fuller glimpse into what my participants experience in each vignette.

To that end, in Chapters 8-10, I open sections with a "vignette" – a short, descriptive narration of a particular interaction that I witnessed during my data collection. Although I add in my own impressions of emotions and thought-processes, I sent drafts of these vignettes to the appropriate participants to obtain their approval, ensuring they agreed with my interpretation of events. Likewise, I sent copies of this data chapter to participants for their feedback, and it has been included in this thesis with their approval.

These vignettes, like the one at the beginning of Chapter 1, are set apart from the rest of the text by using a different font and indenting the entire vignette. A horizontal line is also placed to connote the beginning and end of a vignette, likewise to differentiate the vignette from the rest of the text.

Additionally, when I refer to a participant, I periodically include the site they visited and their disabilities to remind the reader of each participant's experience. This follows my use of the human rights model of disability – whilst the barriers that they face during their museum experience are constructed by society, they still experience physical symptoms due to their conditions. It is very often these symptoms that lead to their needs, and a reminder of their conditions is important to understanding the participant's experience.

In designing this research, it was necessary to follow a 'deficits model' of disability and particularly neurodiversity. In describing their disabilities, my participants very often provided ways in which they were limited in their day-to-day activities due to

these disabilities. As such, my focus during our interviews and site visits was on the barriers that they faced due to their disabilities and thus how they were limited in their interaction with the sites.

It is perhaps an oversight on my part, that in designing research to examine these barriers, I did not also take time to examine ways in which my participants' disabilities allow them to understand these exhibitions and sites through a different lens. It would be fascinating for future researchers to look into this particular line of inquiry. I also did not consider barriers affecting potential strengths from these disabilities - for example, with their anxiety, both Amy and Lisa prefer to pre-plan as much of their trips as possible, which means they are highly organised and detail-oriented. I did not examine how much they could or could not pre-plan our visits ahead of time, nor what that impact had on their enjoyment of the visit. Again, it would be interesting for future researchers to take up this view of accessibility and examine how constricting people's strength perhaps disables them.

Initially, there were concerns regarding the anonymity of my disabled participants. On their ethics permission form, there was a space for them to fill in how they wished to be identified within the thesis. Overwhelmingly, participants used their real name. When it was suggested that I should add a level of anonymity to their identities, this did not sit well with me. Above all, I wished to follow the lead of my disabled participants, so I contacted each of them individually to understand their views on the matter. No one had any objections to using the name that they initially identified with, and so I have kept their names unchanged in this thesis. For a full list of their responses, please see Appendix H.

Additionally, as part of the ethics permission form that participants signed before taking part in the research, there was a section at the end regarding how to withdraw their consent should they want to in the future. Participants were given both physical and digital copies of these forms, and they have my contact details should they wish to change their involvement in any way, including withdrawing fully or merely changing how they are identified in the thesis.

I include citations after quotes from my participants as well, referring to Appendices C and D where I have included interview transcripts and field notes.

## 6.2.1. Pilot Study – Teagan (Abbey House; dyslexia, EDS) and Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS).

Teagan and Kasi are sisters whom I have been friends with prior to my research. From the beginning, both had been open about their disabilities with me, and therefore I asked them to participate in my pilot study, supporting me in shaping the foundations of this research. In addition to their level of comfort, as someone with anxiety, I needed a similar level of comfort as I came to grips with my role as researcher. The pilot study took place in May 2019.

### 6.2.1.1. Disabilities.

**"You can do something as simple as taking a step like I did today, and I sublaxed my knee. And my kneecaps are currently in the incorrect place, and there's something underneath, which makes it feel very strange." –** Teagan on her EDS (Appendix C 8.1).

**"It's all a processing thing. Whether it comes to writing something down, reading something, or just that first comprehension of a word can be pretty hard…. It can be hard for me to understand what it is I'm writing, especially if I don't hear it verbally. I can read a paragraph and nothing has been retained, which is irritating, and it can be hard with understanding how things are pronounced. Drawer. I did not realise it was spelled draw-er. I realised that a few months ago." – Kasi on her dyslexia (Appendix C 8.1).**

Teagan's disabilities include Ehlers-Danlos syndrome (EDS herein) and dyslexia. EDS is a physical condition where a person's body lacks connective tissue, leading to hypermobility and associated physical difficulties (NHS 2021g). She explained it to me this way (Appendix C 8.1):

> My body does not correctly create collagen, so it can affect every connectivity tissue – connection in your body, from eyes, joints, digestion issues, hearts and everything like that. The specific type that we have is the hypermobility type. Of the different types, it tends to be the most benign, but it can also cause a lot of issues. One of the

problems with it is that just because you're feeling good one day doesn't mean that you will continue to feel good the entire day or tomorrow, regardless of what you're doing… So in addition to that, with me, it means it also affects my digestion, so I cannot eat red meat.

Dyslexia is a neurodivergent condition in which a person's brain interprets letters differently, either when reading or when writing, making it difficult to engage with textual information (NHS 2021f). As Kasi put it, "I just lose letters. Okay, and I have mixed stuff up. I have also mixed up numbers for letters. Fours and Rs, of course, for some reason. Okay. Gs and sixes" (Appendix C 8.1). But dyslexia also affects handwriting, with Teagan calling her own handwriting "unfortunate" (Appendix C 8.1).

Both EDS and dyslexia have a heredity aspect to them, meaning that although these conditions can spontaneously occur in someone, they tend to be genetically passed down through a family line (NHS 2021g, 2021f). Indeed, Kasi too has EDS and dyslexia, although she also has been diagnosed with attention deficit hyperactivity disorder (ADHD) and dyspraxia. ADHD is a neurodivergent condition in which a person is unable to focus for long periods of time. Often, they have difficulty concentrating and appear restless (NHS 2021b), and Kasi explained (Appendix C 8.1):

> It's mostly just a focusing problem, I struggle. Even If I'm really engaged in a conversation, I can get distracted. I can end up spacing off, I have been to a lot. And It's very annoying, especially if it's during class. And I'm like, "Hi. We're having a test review." A few minutes later, "class is over? Oh, okay."

Dyspraxia is another neurodiverse condition that affects a person's coordination (NHS 2021e). For Kasi, it makes her exceptionally clumsy. She told me (Appendix C 8.1):

> I also have a tendency to... I will look at something. And If I'm walking, I have no awareness of where I'm walking, I got lost in Alaska that way. Also run into things that way. And fall when I trip over.

Indeed, when we visited Abbey House, she held onto Teagan's arm as we walked, shown in Figure 5 below.

*Figure 5. Kasi holds Teagan's arm as they walk along the pavement.*

In addition to their long-term disabilities, Teagan had a temporary accessibility need in the form of an infant in a pushchair. It is an often-overlooked subject in disability and accessibility studies that some people have temporary accessibility needs that can be completely unrelated to disabilities and impairments. For example, pregnant people and those with very small children have access needs that crossover with wheelchair users and other people with mobility impairments (Lacey 2004, 21). Combined with Teagan's mobility issues and Kasi's coordination problems, the pushchair presented another level of difficulty in their visit to Abbey House.

### 6.2.1.2. Data Collection.

In June 2019, I met Teagan and Kasi at their home for our pre-visit interview. We discussed their disabilities, particularly how, although they have mostly the same disabilities, Teagan has more severe EDS whilst Kasi has more severe dyslexia and associated neurodivergent conditions. Teagan guided me through how she plans a museum trip, showing me the websites she uses (normally the museum's website) and expressed her frustration at not being able to find all the information she would

155

like. In particular, she wanted a floor plan or map of the museum, so that she could pre-plan their route through the museum. When asked, she explained that she needed to prioritise which areas they wanted to see, in case she ran out of energy during their visit. Kasi insisted that she did not pre-plan her museum visits, saying "I leave that to [Teagan]," citing her ADHD as a hindrance to any attempt to plan a visit (Appendix C 8.1). Indeed, by the end of our interview, which lasted about an hour thanks to a few infant-related interruptions, Kasi was struggling to maintain focus, another sign of her ADHD.

Two days later, we travelled together to Abbey House for our site visit. We travelled by bus and train, modes of public transportation with which both women were familiar and comfortable. Unfortunately, there were some difficulties in our journey, such as the lift at York train station being unavailable and causing us to miss our first train. Although we were able to catch a later train, this disturbance highlighted the importance of understanding the whole of a visitor's journey – although we were able to navigate the stairs even with a pushchair, not all disabled people would be able to, thus ending their visit before they ever came close to the museum itself.

Eventually, we made it to Leeds and spent about three hours at Abbey House, the majority of our time focused on the site's Victorian Street and exploration of each of the shops and homes in the exhibition (see section 6.1.1 for more on the site). We took several breaks throughout the visit, stopping whenever we saw a place that the infant could easily play while we sat and discussed our visit thus far. There was an extended rest towards the beginning where Kasi and I sat in the café while Teagan went in search of the toilet to change the infant's diaper, and although we were not tired from the visit itself yet, it was clear that the stress of travelling to the museum had taken its toll.

After our museum visit, we walked to a nearby pub to proceed with the post-visit interview. Once everyone had a chance to sit and eat something, our energy levels recovered, but it was clear that both Teagan and Kasi – and even I myself – were already tired and ready to leave. Despite these low energy levels, both Teagan and Kasi were eager to share their insights into our visit to Abbey House. Both expressed a slight frustration over the abundance of text-based interpretation, something they

were accustomed to and yet they found difficult. Kasi observed that she was unable to touch several of the text panels, further disabling her ability to read the panels and understand the exhibition.

Later that week, I met Kasi and Teagan again in a café to conduct our follow up interview. Both women joked that when they finally reached home, they were so exhausted that they could barely do anything else for the rest of the day. Even Teagan's partner commented on their exhaustion, and I was reminded of the physical impact visits can have, particularly on people with hidden disabilities. Indeed, even after several days, Teagan and Kasi both commented that they were still physically feeling the effects of our visit, although Kasi admitted that her trip to London the day after our visit likely contributed to her exhaustion and pain levels. We discussed our visit to Abbey House, and they confirmed that these "upticks" in pain and exhaustion were something that they expected and indeed planned for when arranging a museum visit.

Additionally, they offered their insights into the pilot study itself, commenting that they felt the design represented a holistic understanding of their experience as disabled museum visitors. They offered suggestions for improvements, such as dismissing my plan for in-depth access audits at each site and altering some phrasing in the questions. They also suggested that I should supply the questions I intended to ask ahead of time. This last suggestion in particular I made sure to embed within my future interactions with participants – as Teagan and Kasi pointed out, people with anxiety or auditory processing issues would greatly benefit from knowing what I would ask prior to actually meeting me.

### 6.2.2. Aaron (Treasurer's House; autism, bipolar disorder, OCD).

**"[OCD] is when you don't enjoy it. So like most of my life, the OCD was just for manifestations. So usually, for most people OCD is a certain thing, but OCD usually hits around 12, 13. I had it when I was like 4. Dad, who was a sergeant in the army, didn't really understand it. So it was like cleaning, quarantine kind of stuff, which evolved to doing things in four, as there were four members of my family. So you get up four times in the morning and go back to sleep, which is impossible. You eat four meals, et cetera."** – Aaron (Appendix C 1.1).

Aaron was recruited through my email campaign, as described in Chapter 5. We met in November 2019, conducting our pre-visit interview, site visit, and post-visit interview in one sitting.

### 6.2.2.1. Disabilities.

Aaron told me he had been diagnosed with Asperger's, a condition that falls under the autism umbrella. Autism is a neurodiverse condition that affects a person's interpersonal communications, sensory input, and other mental abilities (World Health Organization 2021a), although he believed this might have been a misdiagnosis. As he said, "obviously with Asperger's, it's defining characteristic of someone having Asperger's is the inability to pick up nonverbal communication but I don't know, it seems that when I'm on a high, I'm fine" (Appendix C 1.1).

He was also diagnosed with bipolar disorder, a mental health condition that affects a person's moods, often leading to extreme mood swings (NHS 2021d). As he puts it (Appendix C 1.1):

> I have rapid cycling. Okay, so sporadic entirely, so it's not the typical 12 weeks of depression, 12 weeks mania. It could be half a day of madness, half a day of fine. and there's no routine or prediction. So that makes life kind of impossible.

When trying to schedule our interviews and site visits, I encountered great difficulty regarding communication with Aaron. More than once, we had to reschedule our interview to accommodate Aaron. Understanding how his bipolar disorder affects him, I now believe that our difficulty in communication was in part to his bipolar disorder, as a manic episode could prevent him from answering messages in a timely fashion or adhering to a schedule.

As described above, he shared that he had obsessive compulsive disorder (OCD), which is a neurodivergent condition where a person's brain hyperfixates on an intrusive thought and is compelled to act upon this intrusive thought, often in a highly repetitive manner (NHS 2021j). He has experienced OCD since he was a child and one of his coping mechanisms is pipe smoking. He explains (Appendix C 1.1):

> Smoking a pipe is quite meditative. The thing about a pipe is we don't take it back into your lungs. You might get mouth cancer, but you won't get lung cancer. But it

takes around an hour just to pack it perfectly. Like if it's not packed perfectly, it won't smoke perfectly. So you spend an hour just packing the pipe type of thing. And then you have to get a match like you can lay it with a zippo or you can light it but it's not really like anything else. And then you have to be conscious of not taking it back into your lungs. So the whole experience is very in the moment, very present, so I bring a pipe with me everywhere.

The pipe not only serves as a focus for his OCD, but by carrying the pipe with him, it serves as a comfort object, allowing him to focus on the experience of smoking a pipe even when he is unable to do so.

### 6.2.2.2. Data Collection.

Aaron and I met at SPARK, an open-air community space in York. We discussed his disabilities, and there was a great emphasis on his bipolar disorder as we spoke. He told me of his daily routine, much of it spent managing his mood swings. We also discussed his own background and his experience as a teenager with OCD.

From there, we walked to Treasurer's House for our visit. At first, he avoided interacting with the room guides and skipped one room entirely, preferring to use the handheld interpretation boards available in each room. As we progressed, however, he did start to approach some of the room guides, who were all friendly and welcoming towards him, and asked them questions. Many of his questions had little to do with Treasurer's House or Frank Green – a particular question he asked repeatedly was why there was no statue of Oliver Cromwell in York – but the room guides were always attentive and patient with him, even when they did not have an answer for his questions.

After our visit, we returned to SPARK to conduct our post-visit interview. He expressed satisfaction with the experience, although he did not find the site particularly interesting. Despite this satisfaction, he believed that had he identified himself as disabled to any of the room guides, he would have been treated far more negatively, expecting the room guides to "[have a] look in their eyes, hair standing up on their arms, people kinda taking steps back" and to treat him in a "condescending, patronising" manner. As we discussed further, it became clear that this belief was

based on past encounters at other museums, not something inherent to the staff at Treasurer's House.

Unfortunately, I was unable to conduct a follow-up interview with Aaron.

### 6.2.3. Alfie (Barley Hall; dyslexia, monocular vision).

**"My main problem is my sight. So I see out of one eye – everything is 2D. That means that getting around is quite fun. Sometimes crossing a road from the other side is complicated. But at least it's exciting times!" –** Alfie (Appendix C 2.1).

Alfie was also recruited through my email campaign. We met in January 2020, conducting our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a few days later.

### 6.2.3.1. Disabilities.

Alfie's disabilities include dyslexia and monocular vision. Dyslexia, as described in 6.2.1.1. above, is a neurodivergent condition in which a person's brain interprets letters differently, either when reading or when writing, making it difficult to engage with textual information (NHS 2021f). Interestingly, he shared that it was easier to read digital documents rather than printed ones (Appendix C 2.1):

> I guess I'm more used to readings on laptops nowadays. Okay, it doesn't strain my eyes to read it easier. Online, I find that my eyes won't skip lines. Whereas on paper, I'm very careful. It takes a lot longer.

Initially, I was unsure if this comment was in reference to his monocular vision or his dyslexia, but given the experience Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) had with skipping lines (Appendix C 8.3), I believe it is due to his dyslexia.

Adding to the difficulty in reading is his monocular vision, a physical condition in which a person can only see out of one eye, impeding particularly their depth perception (RNIB 2021). As described in the quote above, he can only see in 2D, and he later told me how he considered himself disabled because of how his monocular vision has limited the activities he can participate in: "If I compare myself

to how I was 10 years ago, things are completely different. I stopped doing cricket because I can't see the ball anymore" (Appendix C 2.4).

He was at ease talking about his disabilities, and even shared that if he tires of reading information, he will take a photo of the information, "then if I'm interested later, I can read it" (Appendix C 2.1). There were other coping mechanisms that he discussed, particularly using the zoom function on webpages to make it easier for him to read or asking someone to explain something to him. Interestingly, asking someone to explain something was a coping strategy that Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) employs when visiting museums as well.

### 6.2.3.2. Data Collection.

We met for our pre-visit interview in a café to discuss Alfie's disabilities and to prepare for the upcoming site visit. He was very open about his disabilities and their impact on his daily activity, saying that his monocular vision had the biggest impact. He wears glasses to correct his near-sightedness, although he did mention that his vision has been declining and therefore his prescription has become stronger.

From there, we walked to Barley Hall for our site visit. As we went around the museum, much of our discussion centred around the text panels that hung in each room or were placed near displays. Barley Hall has a mix of larger wall-hanging panels and smaller, hand-held panels, with a varying design palette. Although the panels used the colours and fonts, they were often used in different manners, shown in Figure 6.

*Figure 6. Two interpretation panels at Barley Hall, showing similar colour schemes and styles but utilised in different ways.*

Something that I did not know before my time with Alfie was the impact of contrast and margins on dyslexia, and by the end of our visit, it became a type of game between us, where I would guess which text panel was easier for him to read and he would tell me if I was right or not. However, he did comment that by the end of the visit, he was growing weary of all the reading involved, and wished the site had more aural interpretation.

After our visit, we went to a café to conduct our post-visit interview. Alfie reiterated that he would have liked more audio interpretation, particularly in the areas of the site that had very low lighting. As he already had difficulty reading, the low light only made things more difficult for him. He suggested an app or even downloadable resources that he could play on his phone if installing audio interpretation would be too costly for the site.

A few days later, we met again at a café for our follow-up interview. Again, we discussed the over-reliance on text-based interpretation, and again, he expressed interest in some kind of downloadable digital content. He also told me about the mental energy that it took to read the panels, something I had not considered until he

mentioned it. He liked the hand-held panels over the wall-hanging panels because he could bring them closer to his face or take them to a different area in the room where there was better lighting, making it easier for him to read.

### 6.2.4. Amanda (Barley Hall; heart failure, psoriatic arthritis).

**"My arthritis is psoriatic arthritis, all based on psoriasis. My parents have had severe psoriasis. They had lots of skin problems. I don't have any skin problems, but I have the arthritis that comes with that immune problem. So my arthritis attacks different things than rheumatoid arthritis. So it attacks cartilage, tendons and doesn't actually cause damage to them. It just causes lots of inflammation and pain." –** Amanda (Appendix C 3.1).

Amanda was recruited through the snowball method – another volunteer shared my information with Amanda, who in turn contacted me to participate in my research. We met in November 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a week later.

### 6.2.4.1. Disabilities.

Amanda has psoriatic arthritis, a physical condition which causes a person's joints to swell and stiffen, becoming painful and difficult to move, often significantly impeding a person's mobility and dexterity (NHS 2021m). In addition to the inflammation and pain she describes in the quote above, she added, "I get the general fatigue that all people with this type of inflammatory arthritis get. Chronic fatigue is a problem" (Appendix C 3.1). As she explained to me, her fatigue meant that when she was still working, she reduced her working hours to half time before taking early retirement.

In the mornings particularly, she is very stiff and needs considerable time for her joints to warm up and become ready to move again. She explains (Appendix C 3.1):

> I don't get up as early as I used to, so I need extra sleep. So I even now need an alarm to wake me up more than when I was at work. I can feel like after I've been up for half an hour. I feel like sometimes I just want to go back to bed. It's really hard, really hard to push through. I'm very stiff in the morning. I've got a right hip and my lower back, Spondylosis of the spine is one of the side effects of this arthritis. My lower spine is very stiff. And so yeah. So then as I get going, things loosen up and you know, I need to keep the house really warm because I can't get cold. You know, I

don't like going anywhere where it's cold. If somebody were to say 'shall we go down to such and such today,' I couldn't walk because of my breathing. Yes, I properly wouldn't walk there today. It's too cold.

She also has to plan her time carefully, as physical exertion leads to physical exhaustion. As such, I was mindful to not put our meetings too close together, giving her time to recover but also to not take up too much of her time.

In addition to her arthritis, she also has "a second problem, which I would call it a disability. You know, I have heart failure. Oh, I have what I am being assessed but haven't been listed for transplant" (Appendix C 3.1). Like her arthritis, her heart failure causes fatigue, meaning that she must plan things on a day by day basis. In addition to the fatigue, she also experiences breathlessness, something that I noticed as we went around Barley Hall.

### 6.2.4.2. Data Collection.

I met Amanda at her house to conduct our pre-visit interview. We discussed her disabilities and their impact on her daily life, particularly how she manages the pain and mobility difficulties. We also discussed her interest in cultural activities, particularly museums and gardens. As it was November and chilly, I ensured that she felt well enough to visit a notoriously cold site before we left. Wrapped up in a long coat, scarf, and gloves, she also brought a pillow with her in case she needed to sit and rest during our visit.

We travelled by car to York city centre, parking near to Barley Hall for our site visit. Because of its location in a courtyard down a narrow side street (there's no on-site parking for Barley Hall), we had to walk about 5 minutes from the car to the site. Once inside the museum, we were told that a school was in at the moment but that we could easily avoid them as they were in the schoolroom at the moment. It turned out to be a Special Education Needs and Disabilities (SEND) school, so I was able to briefly observe how Barley Hall adapted itself for such a visit. Specifically, the temporary ramps were set up so that a wheelchair user could cross over the thresholds, seen in Figure 7.

164

*Figure 7. A temporary ramp set up to allow wheelchair users to cross the tall threshold in Barley Hall.*

We did not actually encounter the school group, as the layout of Barley Hall allowed ample opportunity to avoid them. Amanda did like that they were able to set up a temporary ramp, but wished that they would have something more permanent for people with mobility issues, as she found the thresholds particularly difficult to manoeuvre as the visit went on. At one point, we simply sat on a cushioned bench, Amanda using the pillow that she brought, giving us an opportunity to rest. She took several deep breaths, which I interpreted as a coping mechanism to deal with pain related to her arthritis, although I did not clarify this point. She pointed out the low light levels in certain rooms, and the fact that light text on a dark background was difficult for her to read when it came to the text panels. Like Alfie (Barley Hall; dyslexia, monocular vision), she preferred the hand-held panels to the wall-hanging panels, as she could more readily read them.

After our visit, we went to a tea room near the car to conduct our post-visit interview. We discussed the visit, and she made an interesting observation (Appendix C 3.3):

I understand that in York, in an old city, a medieval city, you know there are cobblestones everywhere. It's not easy and I think I would accept that it's part of these places... Sometimes they go to that other end, they overcompensate and it does take away from the experience... you want to feel like you're going somewhere different.

Her comment was in regards to the metal temporary ramp, which did seem out of place in a medieval townhouse, and although she appreciated that it was an accessibility measure, she would have preferred a solution that was more in keeping with the aesthetic of the overall site.

I met with Amanda at her home again for our follow-up interview, and she had clearly been thinking of our visit. Without my prompting, she offered several suggestions for improving accessibility, such as a wooden (or faux wooden) temporary ramp instead of the metal one they use currently. She also offered the option of hanging some kind of knotted rope in each doorway to help people over thresholds, as she struggled with not having anything to grab onto as she navigated the thresholds. She also expressed interest in more hand-held interpretation panels, just as Alfie had suggested. We discussed that, like Teagan (Abbey House; dyslexia, EDS) and Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS), our visit had had a significant impact on her energy levels for several days after, and although I apologised for the inconvenience, she explained to me that she had anticipated this fatigue and had planned for it.

### 6.2.5. Amy (Treasurer's House; anxiety, hypermobility, OCD).

**"If I was stuck behind someone else… someone [that] is slower than me going up the stairs, it's also difficult to be behind them. Like I have to go the speed that I go, if that makes sense. And slowing it down and speeding up, it's painful."** – Amy on her hypermobility (Appendix C 4.3).

Amy was recruited through my email campaign. We met in November 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a few days later.

Amy's disabilities include anxiety, hypermobility, and OCD. At the time she participated, she did not have a diagnosis for her hypermobility but she has since been diagnosed with EDS, the same condition that Teagan and Kasi have, discussed in 5.2.1.1. above. Throughout my research, I still refer to it as hypermobility, as that is how she understood her condition at the time. As with Teagan (Abbey House; dyslexia, EDS) and Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS), there is a constant level of joint pain, particularly in her fingers, wrists, toes, and knees. "Over time these become less painful but I have clear memories of being in agony as a child due to knee and toe pain. I now recognise these occasions as early subluxations" (Appendix C 4.1).

The pain in turn leads to something that was commonly mentioned by other participants: brain fog. The term refers to a slowing down of cognitive function, resulting in "slow thinking, difficulty focusing, confusion, lack of concentration, forgetfulness, or a haziness in thought processes" (Ocon 2013, 1). The exact cause of brain fog is still not understood, particularly as it seems connected to so many different conditions, but for Amy, it "means I can get easily overwhelmed and my pain/fatigue levels can quickly get out of control if I don't manage it" (Appendix C 4.1). Amy is not the only participant who mentioned brain fog. In fact, Teagan (Abbey House; dyslexia, EDS), Amanda (Barley Hall; heart failure, psoriatic arthritis), Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia), James (Treasurer's House; fibromyalgia), and Jessica (Treasurer's House; dyslexia, Irlen syndrome) all reference brain fog in their interviews with me.

Amy also has anxiety, a mental health condition in which a person experiences heightened distress, worry, or fear in relation to a wide variety of situations and issues, making it difficult for them to fully rest (NHS 2021). For Amy, she has experienced anxiety since she was a child; however, she dismisses it as simply being a "worrier." As she grew, however, these worries and anxieties became more specific (Appendix C 4.1):

> Something that causes me a lot of anxiety is other people's health. I often get into thought spirals that lead to panic attacks where I am convinced that someone I love is unwell or in danger. These are extremely damaging to my own mental health but

also to my relationships because it's a lot of pressure to have to deal with in the moment, especially when I'm directing so much anxiety and panic their way.

Her point about the impact on her relationships is illuminating, as not only does it show a striking level of self-reflection on Amy's part, but it also highlights the effects that a hidden disability, especially a mental health condition, can have on multiple aspects of a person's life. Not only does her anxiety make it difficult for her to rest, it similarly puts pressure on those around her to pull her out of a "spiral."

She also has OCD, which I discuss in 6.2.2.1. above. Her experience of OCD differs from Aaron, however, as it is so entwined with her anxiety. Her spirals are typical for OCD, which makes a person hyperfixate on intrusive thoughts, compelling them to act on these thoughts. For Amy, she hyperfixates on the health of her loved ones, whilst her anxiety will supply increasingly alarming intrusive thoughts, and so the spiral begins. She also has certain fixations around food: "I have a very short list of 'safe foods'. Everything else I can't eat. This is difficult to explain because it's not just a 'I don't think this' but it's like my body can't accept that it's food" (Appendix C 4.1).

Additionally, Amy tends to pre-plan quite a lot of her trips. Interestingly, all of her disabilities seem to feed into how she plans. She will plan how to get to a place, finding a route that "requires the least amount of walking and if there are long periods of walking that are unavoidable, I'll look into getting an Uber some of the way or find out if there's a café or somewhere to rest inside" (Appendix C 4.1), an intersection of her anxiety and her hypermobility. Much like Teagan (Abbey House; dyslexia, EDS), as outlined in 6.2.1.1. above, cafés are also a useful location not only to rest, but to manage any onset of fatigue or low blood pressure caused by her hypermobility. However, if there is no café at a location, she will make sure to not only carry some food and drink with her, but also check the site's policy on bringing in food. The night before, she prepares everything she will need for the next day – although she freely admits that she tends to overpack and constantly re-check her bag, something she attributes to her anxiety and OCD (Appendix D 4.1).

### 6.2.5.2. Data Collection.

I met Amy at a café for our pre-visit interview. Unfortunately, the recording device stopped working a few minutes into our interview and, because the café was louder

than I expected, the recording that I did have was unintelligible. I took notes during our interview, however, and also emailed her afterwards to explain the situation. She was kind enough to write out her answers to my interview questions to make up for the missing recording. Relevant sections of her email are included in Appendix C.

Like Alfie (Barley Hall; dyslexia, monocular vision), Amy was very comfortable in discussing her disabilities. She told me about how she did not have a specific diagnosis for her hypermobility, although she thought it was part of a larger health problem and was working with her doctors to determine the cause. She also told me how her anxiety and OCD in particular were linked to each other – each condition made her overthink choices or potential situations, feeding into one another and creating a cycle of intrusive thoughts and anxiety that is difficult to break. This overthinking also leads to a great of mental exhaustion, although with her new EDS diagnosis, I believe that the constant pain associated with EDS is also a factor in her mental exhaustion. She told me the measures she takes when planning a museum visit, particularly what she takes with her to prepare for eventualities, including a bottle of diet coke (in case she needs caffeine and/or sugar quickly), water, pain killers, and a book (a calming tactic if her anxiety becomes overwhelming). In order to "calm" her OCD and anxiety, she also spends time on a museum's website before visiting and spends around an hour the night before preparing for a visit, including checking several times to make sure that she has everything she believes she needs for the visit.

On the day of our visit, we walked to Treasurer's House from the café where we met. As we went around the site, she observed people within rooms to see if a particular behaviour was allowed. For example, she mentioned to me that she was unsure if she could pick up a hand-held interpretation panel to read more about a particular chair she found interesting. However, after seeing someone else pick up a similar panel, she felt comfortable enough to pick up the panel herself. As we headed up the main staircase, she noted the placement of a garland on the banister, saying that if she was having a bad day with her hypermobility, this would have a significant impact on her ability to use the stairs. Throughout the visit, she chatted with each of the room guides, although she did need to sit a few times.

After our visit, we went to a nearby café to conduct our post-visit interview. She clarified several things that I had observed during our visit, particularly her need to sit. She said that whilst it was obvious where a visitor should not sit, it was not always clear where they should. Likewise, she would have appreciated to know what things she was able to touch, rather than an endless list of things that she could not touch. She also would have preferred more directions around the property, such as a suggested route because "I enjoy not having to make any decisions" (Appendix C 4.3), implying that her anxiety meant she was always second-guessing where she should go next.

I met Amy a few days later at a café for our follow-up interview. As with several other participants, she felt physical symptoms the next day. For Amy, it came in the form of leg pain and "brain fog," which I describe in 6.2.5.1. above. She reiterated much of what we had discussed previously, and emphasised that her disabilities mean that her level of impairment varies from day to day, so she may not always know what accessibilities measures she needs. That also feeds into her over-preparing for many of her trips, as her anxiety and OCD need to plan for every eventuality, no matter how ridiculous.

### 6.2.6. Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia).

**"The migraine makes it quite difficult working with computers and things. I have a lot of external triggers, like some lights in shops – I can't go into certain shops because it's just an immediate migraine trigger. That was so severe when I was younger that I'd be taken out of school. So that's quite a problem – I have to plot where I go according to what I can tolerate at the moment."** – Ellie (Appendix C 5.1).

Ellie was recruited through my email campaign. We met in November 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a few days later.

Ellie has several mental health conditions, including anxiety – discussed above in 6.2.5.1. – and depression, a condition in which a person is unable to emotionally engage in their usual activities, often leading to difficulty participating in these same activities (NHS 2021l). For Ellie, her anxiety and depression manifests more as a block in her everyday activities. She told me (Appendix C 5.1):

> Anxiety and depression sort of go hand in hand, in that I get very stressed out very easily... It stopped me from doing things quite a lot in terms of like, trying to get the momentum up to do things. So it's quite draining in that way. Even just simple stuff like doing washing up, it feels kind of like a mental battle to actually get to the point of being able to do it.

The "mental battle" Ellie describes is a symptom called "executive dysfunction," where there is a disconnect between the person's desire to do something and then finding the physical energy to do it (Healthline 2021) and it is a common side effect of clinical depression (McLennan and Mathias 2010; Dunkin et al. 2000). Executive dysfunction is not solely related to mental health conditions, and indeed, many people with chronic conditions or neurodiverse people experience executive dysfunction (Roberts et al. 2017; Grober et al. 2011). From an outsider perspective, the person experiencing executive dysfunction may appear lazy, disorganised, or even rude, but the reality is that the person is, for the moment, incapable of performing a particular task. For Ellie, she is theoretically capable of washing her dishes. However, when she is experiencing executive dysfunction, the dishes are an insurmountable task.

Interestingly, there is a connection between physical impairments and mental health conditions such as depression and anxiety, particularly with chronic conditions like fibromyalgia (Bernik et al. 2013; Buskila and Cohen 2007; Fietta et al. 2007), which Ellie also has. Fibromyalgia is a physical condition that causes pain all over the body, also called "flares" (NHS 2021h). For Ellie, the condition "is constant widespread pain, particularly my joints. For me it tends to be worse in my knees so I walk with a stick for the majority of the time" (Appendix C 5.1). However, like Amy (Treasurer's House; anxiety, hypermobility, OCD) in 6.2.5.1. above, the pain causes extreme fatigue and brain fog for Ellie, "so quite often even simple tasks are really

difficult because I just can't compute what I actually need to be doing" (Appendix C 5.1).

She also experiences chronic vestibular migraines, a physical condition where a person experiences frequent migraines particularly affecting their sense of balance (Johns Hopkins Medicine 2021). For Ellie, these migraines are not only extremely painful headaches "but also, with the particular kind I get, I struggle a lot with dizziness because it affects my inner ear as well, so I got lots of symptoms like motion sickness… sometimes collapsing with visual problems as well" (Appendix C 5.1). The "visual problems" Ellie references are called migraine auras, which are dark lines or spots that appear in a person's vision, normally occurring before a migraine appears (Mayo Clinic 2021). Sometimes, these spots turn into fully blacked-out vision. Unfortunately, two particular migraine triggers for Ellie are linked to digital screens and lighting. She explained that "the migraine makes it quite difficult working with computers and things and I have a lot of external triggers like some lights in shops, like I can't go into certain shops" (Appendix C 5.1). To avoid these triggers, Ellie has to "kind of plot where I go according to like, can I tolerate XYZ at the moment" (Appendix C 5.1) and also uses a screen reader when using digital devices. However, "I tend to use it more on like actual documents as opposed to websites because it does not respond very well to websites" (Appendix C 5.1). The inaccessibility of these improperly formatted websites means that for Ellie, "it's just easier to risk the migraine or just have a quick look rather than wait for my screen reader to battle through the website" (Appendix C 5.1). Considering how debilitating and even dangerous these migraines are for Ellie, the increasing digital-dependency of the world has become a barrier in its own right to Ellie and her disability.

### 6.2.6.2. Data Collection.

I met Ellie at her home to conduct our pre-visit interview. We discussed her disabilities, especially the varying nature of them and how they have become progressively worse as she had gone through university. She also explained to me that out of all her diagnoses, it was her migraines that affected her the most, especially as they are triggered by certain types of light, especially computers. Additionally, she explained to me how she prepared for a visit. Like Amy (Treasurer's House; anxiety, hypermobility, OCD), she tended to pack everything the night before,

including pain killers, anti-nausea medication, her walking stick, and a snack (in case of a migraine or fibro flare), as well as making sure her phone was fully charged in case she needed to call for help whilst she was out.

We then walked to Treasurer's House. Given that we were visiting in November, she was dressed warmly to counteract the cold, as the chill could cause her fibromyalgia to flare up. As we walked through the property, she did eventually bring out her collapsible walking stick, a move I took to mean she was beginning to feel pain in her joints. She liked the hand-held interpretation boards, although she did find them slightly unwieldy when she tried to use them as she held her walking stick. Like Amy, Ellie expressed a desire for a more "official" route to follow, as she wanted to ensure she saw the whole property. She also struggled with the lighting levels, particularly when we moved from a dimly lit room to a bright one. The change in levels, she explained, could potentially trigger a migraine for her. Also, the flame-shaped bulbs that had been installed in some rooms, shown in Figure 8, were particularly painful for her, as they were intensely bright.

*Figure 8. The small but intensely bright bulbs were a potential migraine trigger for Ellie at Treasurer's House.*

After our visit, we walked to a nearby café to conduct our post-visit interview. She expanded on certain things I had noticed during our visit. For example, she pulled out her walking stick because she was having difficulty with the pace of the visit, having to walk for a bit and then stop, which was tough on her joints. She also explained that the lighting levels, aside from being a potential migraine trigger, made it difficult for her to read. She was already experiencing some brain fog, and the extra effort needed to engage with the text meant she tired more easily. She, like Alfie, also mentioned a desire for more audio interpretation aside from room guides.

I met Ellie at a café a few days later to conduct our follow-up interview. As with several other participants, she was extremely tired the day after our visit. She actually expressed surprise about this, however, as she did not expect it to have such an impact on her. She still explained that the lighting levels were the most

significant barrier she encountered, but that it was her fibromyalgia that had the biggest impact on her visit. The continual change in energy and momentum was particularly hard on her hips and knees, areas that are especially affected by her fibromyalgia. She too mentioned the garland on the banister, and although according to her it did not present an extreme barrier, it did have an impact on her ability to use the stairs.

### 6.2.7. James (Treasurer's House; fibromyalgia).

**"Everything hurts. No, no, no. That's as good as anything. Everything hurts. Okay, so knees, ankles, toes, fingers, elbows, shoulders, neck. Everything hurts okay? It comes and goes, sometimes good. Some times are better than normal. Some days are okay. And then other days are horrendous."** – James (Appendix C 6.1).

James was recruited personally as he was a co-worker of mine at the time and had shared with me his journey to a diagnosis with fibromyalgia. We met in November 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a few days later.

### 6.2.7.1. Disabilities.

At the time of his participation, James was recently diagnosed with fibromyalgia, which I describe above in 6.2.6.1. He mirrors Ellie's experience of widespread pain due to fibromyalgia, even explaining that "I've had a couple of days of just chilling on the sofa" (Appendix C 6.1) in preparation for our site visit. He expressed a great relief at the time regarding this diagnosis, as he had been experiencing unexplained pain for years. He called the diagnosis "a bit of a blessed relief – horrible to hear but a blessed relief" (Appendix C 6.1). His expression of relief is a common theme amongst many people with chronic conditions (e.g., Huibers and Wessely 2006), including other participants such as Amy (Treasurer's House; anxiety, hypermobility, OCD) and Jessica (Treasurer's House; dyslexia, Irlen syndrome). A diagnosis can be a vindicating experience for a disabled person, proving their symptoms are not psychosomatic. For James, the stress of constant pain was only matched by the stress of trying to understand the cause of it. He explained (Appendix C 6.1):

175

I just thought it was age. And this is what happens when you get old… I did notice and work did notice that I was taking more and more time off, that I would wake up in the morning in agonising pain, I couldn't understand why I was in agonising pain… So obviously, you have those five and six years of non-stop tests and you know, waiting for appointments and before it was arthritis at one point and all sorts of things. They obviously added stress to my life because not knowing what was causing the pains was a big, big problem.

As his diagnosis was fairly recent, at the time of his participation in this research he was still learning coping mechanisms to deal with the pain and other symptoms. He had connected his Alexa device to his lights, so he could voice-activate them on bad days when "things like turning on light switches could hurt if you just press it on a really bad day and press the light switch pain would just rocket through your body and you'll be useless for the next 20 minutes" (Appendix C 6.1). He planned on adding more voice-activated technology to his home over time when he had the means to do so.

To understand how different actions may take different levels of energy each day, James explained he uses the "spoon method" to measure what he is able to do. The "spoon theory" is popular amongst people with chronic illnesses, who call themselves "spoonies," as a way to explain to nondisabled people why they are limited in what they can do on any given day (Miserandino 2003). As James puts it, "you start off with a number of spoons depending on how you feel in the morning and then grade your activities accordingly" (Appendix C 6.1). "Spoons" can be understood as units of energy or effort, and the amount of spoons a person has will vary from day to day, based on the symptoms of their particular chronic condition. For example, James may start a high-pain day with only 20 "spoons." If it takes 3 spoons for him to get out of bed, another 5 spoons to get dressed, and 2 further spoons to make a bowl of cereal for breakfast, he has already used half of his "spoons" for the day. Ellie also mentioned using the spoon theory to plan her day. She shared that "simple day to day tasks like going to the shop, like having lectures, I have to allot a lot more time because it's just physically exhausting for me and quite often I get back and I just have to like get straight into bed because it just takes up so many spoons" (Appendix C 5.1). The spoon theory then is a useful tool for

176

disabled people to "measure" their day, and something I was cognizant of when scheduling interviews and visits with my participants.

I met James at DIG, another museum run by YAT and one we were both well-acquainted with, to conduct our pre-visit interview. We discussed his recent diagnosis, particularly how it was more a process of elimination than a specific test for fibromyalgia. Prior to his diagnosis, he thought the pain was merely a side effect of growing older, but he had also had additional stress because of the pain for over five years now. He told me that he uses a walking stick to move around sometimes, and is comfortable enough to cancel plans if he is having a particularly bad day.

We walked to Treasurer's House from there. During our visit, James did not use his walking stick, although he did sit several times. He noticed the lack of handrails in many locations, and a particular irritation of his was the garland on the banister. Because of the lack of handrails, he held on to walls, columns, and even the garland in order to climb steps. In one of the rooms, a room guide showed us the detailing on a particular piece of furniture, pulling out a handheld torch to show us. I discuss this small act later in Chapter 8, but James and I both found it interesting that the lighting was so poor in the room that a handheld torch was needed to see the intricate detailing on a primary feature of the room.

After our visit, we walked to a nearby café to conduct our post-visit interview. Again and again, James mentioned the lack of handrails and especially the garland tied to the banister as barriers that stood out to him. He also would have liked more seating and, as mentioned by Ellie and Amy, more directions throughout the property.

I met with James a few days after our visit to conduct our follow-up interview. He told me he experienced more pain the day after, but he had anticipated this. He once again reiterated the banister as his enduring memory of the visit, and hoped that this would be remedied soon.

### 6.2.8. Jessica (Treasurer's House; dyslexia, Irlen syndrome).

**"With Irlen syndrome, it's a light sensitivity and disability. So for example, if there's really harsh lighting, or if there's lots of like, you know, writing on a page like this, and I find it quite hard to read it because my brain is kind of working really hard. And that's when I kind of started to get a bit tired and a bit stressed and a bit frustrated."** – Jessica (Appendix C 7.1).

Jessica was recruited through my email campaign, although I had known and worked with her previously. She had not been diagnosed when we first met, although she had been dealing with the impact of her disabilities all her life. We met in October 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview a few days later.

### 6.2.8.1. Disabilities.

Like James, Jessica had received her diagnosis not long before she participated in my research. She has dyslexia, which I discuss in 6.2.1.1., and also Irlen syndrome, a neurodivergent condition where a person's brain interprets light differently, often leading to difficulty reading and writing (Irlen 2021). For Jessica, it is difficult to separate the two conditions, as there is considerable overlap between both the symptoms and the side effects of each. No matter which condition is responsible for it, she explained to me that "I particularly struggle with spelling and reading and stuff like that and being able to find the difference between different types of words" (Appendix C 7.1).

Both her dyslexia and Irlen syndrome had a significant impact on her reading and writing ability, and as she told me, "it's not because I'm stupid, it's because I have a disability and I just need some extra tools to do for me to be able to read and excel in studying" (Appendix C 7.1). The additional tools include her colour overlay, which I discuss further in Chapter 8, and screen reading software. The screen reader particularly is to aid her in her degree, as her disabilities make it difficult for her to edit her writing. As she said (Appendix C 7.1),

> Instead of having to kind of just sit there and read, I can just have it read to me. And basically when I was proofreading in my work and stuff like that, I could read it 1,000 times but I wasn't seeing any spelling mistakes. But as soon as it's being read aloud

to me, I can easily kind of point out 'Oh, I've used a wrong spelling there,' or 'I've misspelled that,' or 'that's probably when I could use a new sentence or a new paragraph' or stuff like that.

Her preference for auditory means of processing information was something she commented on later when we were discussing museum visits. She told me that she always checked if a museum had audio guides, "because I know that I will learn better about the museum rather than just standing there and reading" (Appendix C 7.1).

However, the impact of her disabilities extends beyond her reading comprehension. Like Ellie's vestibular migraines, Jessica's Irlen syndrome means that certain kinds of lighting have a significant physical impact on her. She shared (Appendix C 7.1):

In Primark a few times when I was younger, I did pass out and obviously I just didn't realize what it was [at the time]. But when I had my tests for my Irlen in July, I did mention about the lights in Primark, that sometimes I did pass out, and [the test proctor] was like, 'Yeah, I've had lots of people mention that before.'

As will be discussed in Chapter 8, lighting conditions can present a significant barrier for many people in public buildings, especially museums.

### 6.1.8.2. Data Collection.

I met Jessica in her home to conduct our pre-visit interview. She told me about her disabilities and particularly how she had been adapting since her recent diagnosis. Like James, there was a sense of relief, knowing there was a reason she had such difficulty reading and writing. She showed me some of the accessibility tools that she had started using, such as special software that reads text to her and a coloured overlay that she used on printed materials. She pointed out that the overlay was small enough to fit inside her purse so that she could carry it around and use it even when she was out. When preparing to visit a museum, she tends to carry out extensive research on the place, referencing documentaries, YouTube, and podcasts as particular sources of information that utilise audio formats. She would also check to see if there were audio tours available to hire at a site, once again showing her preference for audio information.

From there, we walked to Treasurer's House. As we went around, she particularly liked the hand-held interpretation panels, especially because they were printed with an off-white background, something that helps both her dyslexia and her Irlen syndrome. She also used her overlay quite a lot, and although earlier she had said that she was self-conscious about using the overlay in public, she felt confident using them in this setting because no one else could see it whilst she was holding the panel. She did note that the lighting was quite dim, making her struggle somewhat with reading. There were also laminated sheets that she picked up to read, but given how shiny the surface was, she did not bother trying to read them and simply put them back. Continuing through the site, she wondered if it was possible for the property to put PDF copies of these interpretation panels on their website for visitors to download and read in their own time (and, presumably, with their own screen readers or other accessibility aids).

Afterwards, we walked to a nearby café to conduct our post-visit interview. She reiterated a lot of what we discussed whilst going around the site, particularly the impact of lighting on her ability to enjoy her visit and also the reliance on written interpretation. She was somewhat disappointed with her overall visit, as she was eager to learn about the house and its last owner, Frank Green, but could only access that information by speaking to room guides. She liked the hand-held interpretation panels, but she had a difficult time engaging with them.

A few days later, I met Jessica at a café to conduct our follow-up interview. Once again, she emphasised the lighting issue, telling me that she ended up having a headache after she left our final interview. She also said that she was unlikely to revisit, as she could not engage with the material and, as she put it, could therefore not have a meaningful experience.

### 6.2.9. Lisa (Abbey House; general anxiety).

**"I went to a Thai restaurant with some friends for their birthday. And I had to look online and I was like, 'I can't pronounce anything. I don't know what these things are.' So I just went with the Tikka Masala because I know what that is."**
– Lisa (Appendix C 9.1).

Lisa was recruited through my Twitter campaign. We met in November 2019, conducted our pre-visit interview, site visit, and post-interview in one sitting, with a follow-up interview over the phone a few days later.

### 6.2.9.1. Disabilities.

Lisa has general anxiety, initially discussed in 6.2.5.1. above, but hers is particularly focused around social situations. As she explained, "I can't just go out somewhere, I have to kind of think about how I look and think about how I'm going to get somewhere, whether that's parking or buses, it's kind of planning to the extreme" (Appendix C 9.1). Understandably, it has had a significant impact on her social life (Appendix C 9.1):

> It means that I cancel my plans a lot. I don't always give the real reasons for cancelling. So you know I might tell my friends I'm really sorry and I know it was gonna come out but this has come up yeah. Or sometimes like it causes migraines, you know I have to cancel just because I'm just generally not feeling well.

The physical side effects of a hidden disability are a common theme amongst my participants. By 'side effects,' I mean a physical symptom that is not intrinsic to the condition itself. For example, Teagan's EDS means her body does not create enough collagen (NHS 2021g). However, the side effects of her EDS include her body's inability to digest red meat (Appendix C 8.1). For Lisa, her anxiety can lead to migraines. Nearly every participant has described to me a side effect relating to one or more of their hidden disabilities, making it all the more important to take the lived experience of people with hidden disabilities seriously. The information regarding these side effects is not something that is discussed in the literature about these conditions, and by asking my participants about their disabilities, I believe that my research is far more thorough than if I had limited myself to published studies.

### 6.2.9.2. Data Collection.

I met Lisa at Kirkstall Abbey to conduct our pre-visit interview. We discussed her disability, particularly about how her anxiety was mostly social. She often cancels plans with friends or plans these outings to an extreme, even practicing what she would order at a restaurant so that she did not have a panic attack when ordering. Likewise, when planning a museum visit, she plans out every detail. Not only does she scour a museum's website, she also checks their location on Google maps,

particularly street view so that she knows what the building will look like when she arrives there. Much of this matches with what Amy and Ellie, who also have anxiety, described when they plan outings.

We then crossed the street to Abbey House. She explained to me that her partner works for Leeds Museums & Galleries, the organisation that runs Abbey House, but that she was feeling slightly anxious about visiting anyway. Because of her anxiety, I did not record our visit through the museum. As we moved through the museum, I noticed that she avoided areas where there were groups of people already milling about. She also tended to look more at the objects than the accompanying interpretation. Our visit was brief, something I assumed was due to her nerves.

After our visit, we walked to a nearby pub to conduct our post-visit interview. Lisa seemed far more relaxed in that environment, and when I asked her, she said that she was worried about what the staff members were thinking of her. She also clarified that she was avoiding the areas where people were congregating, as it was too crowded in those areas and it made her nervous. She also wanted museums to have more quiet hours, although she was unlikely to use them as she did not want to crowd people who "deserved it" more than she did (Appendix 9.2).

A few days later, Lisa and I conducted our follow-up interview over the phone. She told me that the evening after our visit, she had a panic attack. She was rather surprised by this, as she did not expect to be so impacted by the visit. She was also tired the next day, another thing she did not expect. However, she was still enthusiastic about participating. She reiterated that she did not enjoy the crowded areas, and tried to avoid them as much as she could. She also revealed that she did not view herself as disabled. Given that I had already caused one panic attack, I did not pursue this particular line of questioning, but reflecting upon this comment and also that she did not like to use accessibility tools so that other "more disabled" people could use them, I wonder if her anxiety regarding how people viewed her led to this particular viewpoint.

### 6.2.10. Teagan – Barley Hall Follow-up.

As will be discussed in Chapter 6, all my case study sites changed and adapted to the COVID-19 pandemic. Ideally, I would have liked to take a participant around each site to comment on the changes, but time and circumstances did not allow for this. Teagan kindly offered to visit Barley Hall with me, to give her insights into the changes. Although she had not visited this site as part of my research, she was familiar with the pre-COVID-19 experience and could contrast that knowledge with their current experience.

I conducted our visit in the same manner I had conducted other site visits: I followed Teagan's lead, allowing her to explore the site at her pace. She mourned the lack of interactive elements, a feature she had enjoyed greatly in the past, but she expressed excitement at the availability of the map. She did point out some design features that would make it more accessible for visitors with dyslexia, particularly the contrast of the white text within black boxes. She also commented that, upon entering the Steward's Room, the placement of a table meant she had to make a particularly hard right-angle turn, something that was difficult for her due to her EDS and, she presumed, also difficult for people with other physical or mobility difficulties.

Given that we had conducted a pre-visit interview during the pilot study (see 6.2.1.2. above), I did not repeat this interview with her. Instead, we conducted the site visit as outlined in Chapter 5, as well as a post-visit interview, again outlined in Chapter 5. I did not record audio for this site visit or interview, but my field notes and diary can be found in Appendices D and E.

## 6.3. Summary.

Throughout this chapter, I have presented the data I collected from both participants and case study sites. Through semi-structured interviews, onsite visits, and observations, I gathered a significant amount of data regarding the barriers that my participants faced, as well as the organisational responses to these barriers. In the next chapter, I examine the impact of the COVID-19 pandemic on both my research and the heritage sector at large, and discuss the changes that each case study site

put into place in response to the pandemic. I also consider the impact that these changes have on the accessibility of the site.

# Chapter 7 – COVID-19 and Its Impacts.

On 31 December 2019, the World Health Organisation was informed of an outbreak of a virus that would come to be known as the COVID-19 novel coronavirus, centred in Wuhan City, China (Andersen et al. 2020). In January, the virus was identified and sequenced, adopting the name COVID-19. On 31 January 2020, the first cases in the UK were detected in York, and from there, the virus spread to the rest of the country. As of November 2021, over 263 million cases have been diagnosed worldwide, with more than 5.2 million fatalities (World Health Organization 2021d). In the UK, over 10.3 million people have tested positive for the virus, with over 145,000 fatalities (World Health Organization 2021d). Even with the advent of vaccination programmes, the virus is still mutating, causing considerable concern and leaving a profound impact on the world, the heritage industry, and this research.

In this chapter, I begin by briefly discussing what COVID-19 is, along with the newer condition of Long COVID. I then discuss the necessary pivots that took place in my research as a consequence of the pandemic, whilst also considering how the pandemic the other doctoral research. I then turn to the implications of the pandemic on the heritage sector as a whole. Next, I discuss how, as lockdowns and restrictions came to an end, museums and heritage sites were able to re-open, and I position these re-openings around a discussion of associated governmental reopening guidelines as well as the Seven Principles for Inclusive Recovery. The latter have been created by the UK Disability Arts Alliance in order to ensure disabled people are not excluded from recovery efforts in the name of expediency. Adapting the governmental guidelines and the Seven Principles as a framework, I explain the accessibility-related changes that were made to each of my three case study sites. Finally, I discuss these changes in terms of their impact on the accessibility of the sites.

## 7.1. COVID-19 Novel Coronavirus.

The SARS-CoV-2 virus, commonly referred to as COVID-19, is primarily spread through droplets of saliva or nasal discharge, such as when a person speaks or sneezes. Symptoms of the disease include fever, a dry, persistent cough, and the loss of taste and/or smell (World Health Organization 2021c). More serious infections require hospitalisation, as the illness can cause chest pain, difficulty breathing, and even loss of speech or movement. As the pandemic persisted, it became clear that certain communities were more affected by the virus- and more seriously – than others. Although there has been research into the racial, socio-economic, and gender disparities in COVID-19 patient demographics, the link between underlying (chronic) conditions and more serious COVID-19 symptoms is especially relevant for my research. As may be expected with a virus that causes respiratory distress, people with chronic conditions such as asthma, COPD, and other lung conditions are considered especially vulnerable (NHS 2021k). In addition to people with lung conditions, a variety of other chronic conditions are considered to put people at high risk, such as epilepsy, heart disease, and – relevant to this research – arthritis and other joint conditions. Recall that several of my participants have joint conditions: James and Ellie both identify as having fibromyalgia, Teagan, Kasi, and Amy as having EDS, and Amanda as having arthritis. Exactly why these conditions present a greater risk of more serious COVID-related complications is still being explored, but even early on, the UK government identified people with certain chronic conditions as being "at risk" and asked them to "shield" or stay at home to avoid exposure to the virus (NHS 2021a). Disability activists have rightly called many of these measures discriminatory, putting undue responsibility on disabled people who already face barriers in their everyday life (Pring 2021a; Shoosmiths 2021) and further isolating them from their workplaces and social situations. A side effect of the pandemic has been a surge in mental health issues stemming from the multiple national lockdowns and the isolation that people subsequently feel (Abbott 2021; Mental Health Foundation 2021), but little has been reported on the intersection between chronic conditions, shielding, and mental health. It should be remembered from Chapter 6 that chronic conditions and mental health conditions are often comorbid, and therefore disabled people are very likely experiencing even greater mental health

issues than their nondisabled counterparts, especially with government-mandated isolation still being advised more than a year into the pandemic (NHS 2021a).

In 2021, a new phenomenon emerged, called "Long COVID" (NHS 2021i). For most people, symptoms of the virus last 10-14 days. However, for a small percentage of those infected, the symptoms do not fully disappear. In fact, one of my participants, Teagan (Abbey House; dyslexia, EDS), did contract the virus, and although she recovered, she became a Long COVID patient. Her symptoms, including breathing difficulties and severe fatigue, were persistent even eleven months later. Over a year after the initial illness, she still has difficulty walking and talking at the same time and has had to reduce how many hours a day she can work at her job. Interestingly, once she received the first dose of the vaccine, her Long COVID symptoms cleared up within three weeks. She is not alone in her experience (Kingsland 2021), and there could be profound implications for other chronic conditions if this reversal is better understood (Grover 2021). Chronic fatigue syndrome in particular is one condition that, as well as often being a post-viral condition, may benefit from some form of vaccine therapy (Marshall 2021). Additionally, there have already been calls to consider Long COVID a disability (ACAS 2021; Trade Unions Congress 2021). Should these calls be heeded, it would not only increase the disabled population, but it also has the potential to shape discussions around disability and inclusion, as a large number of previously healthy, nondisabled people are suddenly excluded from aspects of their previous lives due to their new disability. Although nondisabled people become disabled every day, the collective nature of Long COVID could prove to be a catalyst for positive change.

## 7.2. COVID-19 and this Research.

On 31 January 2020, the first cases of COVID-19 were recorded in the UK in York (BBC 2020). At that time, I was in the process of gathering data with my participants and setting up observation dates with my case study sites. In March 2020, a national lockdown was announced, forcing the closures of all non-essential locations, including museums and heritage sites. Data collection on this research was paused and instead I focused on data analysis, waiting for sites to open again. However, as the lockdown continued, it became apparent that when sites did open again, they

would be profoundly changed due to COVID-19 adaptations. Through discussions with my supervisor, I decided that data collection from participants had come to an enforced end. The pre-COVID museum experience no longer existed, and to compare that with a post-COVID museum experience seemed unequal, even when looking at the same site, because so many adaptations to each site had occurred.

Additionally, and more importantly, it seemed inappropriate to ask people with hidden disabilities to accompany me on a museum visit and potentially expose them to the virus. I was not the only researcher to face such a decision: doctoral researchers across the globe were forced to pause and adapt their research projects (Levine et al. 2021; Bradt 2020; Johnson et al. 2020; Radecki and Schonfeld 2020; Wang and DeLaquil 2020). As Brandt writes (2020, 297-8):

> Although flexibility and responsiveness are core characteristics of qualitative research, few researchers would have anticipated the extent of responsiveness needed in their research. For some researchers, their very research questions may have become irrelevant or even trivial in light of this pandemic.

Particularly for interpersonal research that relied upon in-person interactions, the pandemic and ensuing lockdowns meant that not only did research frameworks need to adapt, but so did the pool of participants that researchers could connect to (Levine et al. 2021; Radecki and Schonfeld 2020). For some researchers, this meant delaying fieldwork opportunities until the pandemic subsided (Radecki and Schonfeld 2020), whilst others were forced to cancel fieldwork altogether (Levine et al. 2021). As mentioned above, I prematurely concluded my fieldwork with participants in response to the pandemic.

One of my participants, Teagan (Abbey House; dyslexia, EDS), did contract COVID-19 and then, as previously discussed, developed Long COVID. Seeing the impact of COVID-19 on her physical health only encouraged me that the decision to stop data collection with participants was the right one. Within the research presented in subsequent chapters, there is therefore an imbalance in the representation of disabilities, in the number of visits to each site, and in my own observation days at each site. As noted in Chapter 6, I had completed five site visits with participants to Treasurer's House as well as five days of ethnographic observation there by the onset of the pandemic. However, I had only conducted two site visits with

participants to Barley Hall and two visits to Abbey House by that same point, and I had not conducted any ethnographic observations at either site. As explained in Chapter 5, I originally tried to find a balance in representing physical chronic conditions, neurodiverse conditions, and mental health conditions when recruiting participants. In actuality, almost all my participants had a physical chronic condition, about half had a neurodiverse condition, and one third a mental health condition. Despite this, there was enough data to draw out the conclusions I reached in the previous two chapters. If I had been able to fully complete my data collection, further themes may have emerged, but I have no doubt that the themes addressed in Chapters 8 and 9 would have still been represented. This is because these two particular themes were persistent across all types of disabilities and arose at all three case study sites, both via my participants and also in discussions with staff members.

As the pandemic progressed and museums adjusted and began to re-open, I re-visited each of my case study sites to see first-hand how they had adapted to the changes. I was able to interview staff members at both Abbey House (n=4) and Barley Hall (n=2), allowing me to gather the staff-centric data that I had already gathered at Treasurer's House. Unfortunately, I was unable to speak to any staff at Treasurer's House because the site did not reopen until May 2021. Once they finally did re-open, no one at the site returned my inquiries. Thus, I was unable to determine their views on the COVID-related accessibility changes in the same way as I did with staff at Abbey House and Barley Hall. However, as I mentioned in Chapter 6, I was able to speak to Dr Heather Smith, Equity Officer for the National Trust, about my research.

Additionally, Teagan reached out to me and offered to audit Barley Hall with me to give her insights into their COVID-related accessibility changes. As hesitant as I was to take any further participants around the sites, she had already contracted the virus at the beginning of lockdown (more than a year prior to our Barley Hall visit) and had also received both doses of the vaccine, so her risk of contracting the virus was extremely low. Although she was not one of my original participants for Barley Hall, she had visited the site before the pandemic and was familiar with the experience. Of the two original participants who went to Barley Hall with me, Amanda was still at

high risk of exposure due to her heart condition, and I could not get in contact with Alfie because his contact details were no longer valid. Teagan, therefore, seemed an ideal substitute as she too had a similar physical condition to Amanda and she also had dyslexia, just as Alfie did. It was not a perfect solution, but given the extreme circumstances, it seemed the best possible course of action.

Obviously, when I began this research, I could not have foreseen these circumstances. However, by harnessing the opportunities that these setbacks have presented, it has steered me into a new avenue that could not have been predicted. The next section explores this unanticipated opportunity, examining how each case study site made themselves "COVID secure" and the subsequent impacts of such COVID security on the accessibility of the site. I include Teagan's observations throughout the discussion where applicable.

## 7.3. COVID-19 and the Heritage Sector.

Put lightly, the COVID-19 pandemic had a profound impact on the heritage sector. Rarely is there research done on COVID-19's impact that does not mention "widespread damage to the Museum industry" (Choi and Kim 2021, 13; e.g., also Antara and Sen 2020; Crooke 2020; Guest 2021; Pennisi 2020). As with other sectors, heritage professionals were forced to essentially adapt or close permanently – but first, they had to brace themselves for the first wave of the pandemic. A National Lottery Heritage Fund survey, published in March 2020 during the first three weeks of the initial national lockdown, reported "98% of [heritage] organisations had been affected… A large part of the impact was financial – loss of revenue was the second most frequently reported impact (69%), after cancellation of events (91%)" (Guest 2020, 6). A later report from Oxford Economics projected a £3.9bn turnover loss for the museums, galleries, and libraries sector (2020, 43). As the pandemic progressed, it was clear that the financial situation of many heritage institutions was only growing more and more dire. According to a report from the Heritage Alliance, "some heritage charities have seen their non-grant income fall by 80-90%" and "46% believe they cannot survive for another six months" (The Heritage Alliance 2020, 2). Indeed, my case study organisations and sites were not immune to these shocks. The JORVIK Group was forced to close two of their five sites (the Richard III

Experience and the Henry VII Experience) until further notice, and Treasurer's House remained closed for the whole of 2020, not reopening until May 2021. The full extent of the economic impact of the pandemic is still to be seen, but it is clear that the crisis has left the heritage sector profoundly changed.

In addition to the financial implications, new ways of operating had to be developed almost instantly. Given that physical sites had to close, the logical choice was a pivot to digital engagement, and many organisations rose to the challenge. With more people spending time online and on social media (Kemp 2020), museums could attempt to stay relevant and in the public eye by transitioning online, something that scholars such as Nina Simon have been advocating for years (Simon 2007; Simon et al. 2006). Interestingly, Choi and Kim point to this as a natural evolution of the museum experience in general (2021, 4):

> The interests of museums have changed from 'object-based epistemology' to 'object-based discourse,' and that the introduction of new technology has transformed the 'object-centred museums' into 'experience-centred museums'. Experience-oriented museums have become discovery spaces. Moreover, online museums expand user activities. Hence, museums linked to new digital technologies are highly likely to develop into user-centred spaces.

All three of my case study sites are experience-oriented sites, yet none of them changed to a fully digital format. That is not to say that the organisations did not produce online content during the pandemic, as each of them did, but rather that their content was not related directly to these specific sites. For example, Abbey House began posting videos introducing new Makaton[5] signs to followers (Abbey House Museum 2021). Although these videos show a dedication to accessibility, they are not related to Abbey House itself, and I therefore do not consider them here. For this chapter, I focus on the physical, on-site experience of my case study sites.

## 7.4. Re-opening Methodology.

During the first national lockdown, museums and heritage sites were forced to close along with other non-essential places. As restrictions began to be lifted, locations

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[5] Makaton is a sign language system that, unlike BSL, follows the syntactic structure of spoken English. It is used by a wide variety of people, disabled and nondisabled alike. It is even taught to pre-verbal children to give them a way to communicate (Makaton 2021).

had to make themselves "COVID secure" – signalling to visitors that they have taken all necessary precautions as outlined by the UK government and Health and Safety Executive (Health and Safety Executive 2021). These precautions include:

- A COVID-19 risk assessment;

- Cleaning, handwashing, and hygiene procedures;

- Enabling people to work from home where possible;

- Maintaining 2m social distancing where possible;

- Managing transmission risks where social distancing cannot be maintained.

Additionally, face masks were made mandatory inside all public buildings, including museums and heritage sites. Exemptions were made for disabled people who were unable to put on a mask because of their disability or who would experience "severe distress" if they had to wear one (Department of Health and Social Care 2021). Although the government created "face mask exemption" cards for people to use as a way of explaining their lack of face covering, many people started wearing a sunflower lanyard to signify their exemption. A fuller discussion of the sunflower lanyard scheme and its use during the pandemic, as well as its implications for the disabled community, are discussed in Chapter 9.

In order to comply with the governmental guidelines, many museums – and indeed the wider tourism sector at large – had to adapt their pre-pandemic operations. As heritage sites grappled with these changes, the UK Disability Arts Alliance published their "Seven Principles for an Inclusive Recovery." Born out of a concern that disabled people would be left behind, the principles were designed "to ensure deaf, neurodiverse and disabled people are not discriminated against as creative work begins again and as venues re-open" (UK Disability Arts Alliance 2021a). In summary, the principles are:

1. All activities must comply with The Equality Act (2010).
2. The Social Model of Disability is the preferred understanding of disability, and therefore organisations should work to remove barriers rather than enforce them.
3. Co-production with disabled people is paramount.

4. Information regarding COVID-19 procedures must be shared with visitors and employees alike, particularly disabled visitors and employees, so that they may assess their own level of risk.
5. The visitor journey should be mapped and clearly communicated so that disabled visitors may assess their own level of risk.
6. Disabled artists should be prioritised in new creative projects.
7. Diversity should be celebrated, and new ways of working and visiting should highlight this diversity rather than enforcing older, ableist methods.

The Seven Principles tout themselves as "practical guidance to arts and cultural organisations" (UK Disability Arts Alliance 2021a), and have been welcomed by many disabled artists (UK Disability Arts Alliance 2021b). Drake Music, a national organisation working in music, disability, and technology, writes (Meijer 2020):

> As restrictions change and venues and cultural spaces begin to re-open there is a very real concern that Disabled people will once again be forgotten and discriminated against, that the ableism engendered by the pandemic will become part of 'the new normal'... We have a unique opportunity here, to recover from COVID as a stronger, more inclusive, diverse, creative and welcoming sector. [The Seven Principles] can be the roadmap for us all to follow to a better 'normal'.

Indeed, the UK Disability Arts Alliance's website provides a Twitter thread initiated in August 2020 using the hashtag "Inclusive Recovery" (UK Disability Arts Alliance 2021b), with many tweets declaring their support for the discussion and the importance of remembering disabled people when creating reopening plans.

In reading through the Principles, many align with the methodology that I have designed for my own research. Although this research is not necessarily beholden to the Equality Act, I have embedded accessibility and reasonable adjustments into the design of my data collection, particularly with my participants. I position disability mostly in accordance with the Social Model of disability, as discussed in Chapter 1. My research emphasises the voices of my participants with hidden disabilities, embracing an emancipatory framework. I believe the visitor journey, especially disabled visitors, begins long before they physically enter a heritage site, and thus I asked my participants about how they plan and prepare for a visit. The Seven

Principles represent an important framework for an inclusive mindset, particularly for long-standing disability advocates.

However, within the Seven Principles, there is limited practical advice, instead outlining attitudes that must be in place when considering COVID-19 measures. For example, although studies have shown that changing nondisabled people's negative attitudes towards disabled people are not as difficult as perhaps feared (Schitko and Simpson 2012; Bizjak et al. 2011; Daruwalla and Darcy 2005), there is no advice in the Seven Principles about how to implement these more inclusive, anti-ableist attitudes. The only truly practical principles (Principles 4 and 5) involve the dissemination of information – but they are rather vague on what information should be included. According to 2020 research from VocalEyes, potential visitors could "often or always" find relevant access information 38% of the time when they looked for it (Cock et al. 2020, 9). This means nearly two-thirds of the time when someone needs this information, they are unable to find it. So then what information should be included in COVID-19 materials? The Seven Principles are silent on this.

As discussed in Chapter 5, I designed my methodology to enact practical change at my case study sites. Although the Seven Principles represent a truly inclusive mindset, they lack practicality. I therefore use these principles as a foundation for my own framework for analysing the COVID-19 measures put into place at my case study sites.

Accordingly, to assess the impact of the COVID-19 measures on the accessibility of my case study sites, I examine the following areas:
1. Dissemination of COVID-19 information (section 6.5.1);
2. New COVID-19 measures (section 6.5.2);
3. Alterations due to COVID-19 (section 6.5.3).

I focus on these three topics specifically to understand the impact of COVID-19 on the accessibility of my case study sites, as well as to contrast their new "COVID secure" design with what my participants experienced pre-COVID. By focusing on these three areas, I demonstrate that accessibility both increased and decreased at my case study sites, presenting unique challenges as well as opportunities in designing the pandemic-induced changes. In the subsequent sections, I examine

these areas using data from ethnographic observations, interviews with staff members, and information from each case study site's website, as well as Teagan's observations from our visit to Barley Hall.

## 7.5. Analysis of COVID-19 Measures.

Although there are a great number of COVID-19 security measures that are common across all three of my case study sites, I must pause to explain the impact of the national and local lockdowns on the sites.

In March 2020, the first national lockdown was announced, forcing the closure of Abbey House and Barley Hall. Treasurer's House was already closed but had planned to re-open in April, as per their usual seasonal routine. Most employees were put on furlough, utilising the Job Retention Scheme in which the government would pay a percentage of the employee's wages (HM Revenue & Customs 2021). This lockdown was initially supposed to last 12 weeks, but was extended another three weeks. In late June 2020, the first national lockdown was lifted, allowing museums to re-open, provided they had COVID-19 measures in place. Both Abbey House and Barley Hall reopened, but Treasurer's House remained closed.

In October 2020, a tier system for local alert levels was introduced in an attempt to avoid another national lockdown but to allow for local lockdowns (Walker 2020). At the time, neither Leeds nor York were placed into Tier 3, which would require the closure of museums. Abbey House and Barley Hall remained open, but Treasurer's House was still closed.

In November 2020, a second national lockdown was announced, set to last for the month of November. Once again, all museums were closed and most staff members were furloughed.

In December 2020, the second national lockdown was lifted but the local tier system was strengthened, meaning that some areas would still remain in lockdown. Leeds was designated a Tier 3 area (Leeds City Council 2020), and Abbey House remained shut, keeping most staff members on furlough. Barley Hall was able to re-

open, but Treasurer's House remained closed. The first COVID-19 vaccine was administered in the UK on 8 December (NHS 2020).

In January 2021, a third national lockdown was introduced, meaning that once again, all museums had to shut and most staff members were placed on furlough. A vaccination programme began in the UK, inviting people with underlying health conditions and older people to receive the vaccine first.

In April 2021, the third national lockdown was lifted, allowing museums to re-open. For the first time since December 2019, all three of my case study sites were open again, although each had seen significant changes to their visitor experience.

In looking at the timeline of national and local lockdowns, there is an unevenness to the openings and closures. For Abbey House and Barley Hall, closures were dependent on lockdown restrictions, whilst Treasurer's House remained closed for different reasons altogether. In personal communications with my Thesis Advisory Panel member Dr Heather Smith, Equity Officer for the National Trust, she explained that the National Trust categorised their indoor properties into "Treasure Houses" and "Little Gems," allowing them to prioritise reopenings. "Treasure Houses" – not to be confused with Treasurer's House – are larger properties with a more significant collection, whilst "Little Gems" are locally important but not nationally significant by the National Trust's standards. Treasurer's House was designated a "Little Gem" property, meaning that it was not prioritised for reopening as the National Trust worked through the logistics of adapting all their properties to new COVID measures. By the end of the third national lockdown, the National Trust was finally confident enough in their COVID measures to reopen Treasurer's House.

The differences in these reopening timelines are significant not only when considering the flexibility of the case study organisations, but also when considering the impact on my ability to gather data regarding these changes. Because Abbey House and Barley Hall stayed open as much as they could, staff members were also available for me to interview. Given the pandemic, I did not conduct face-to-face interviews until the summer of 2021, but I was able to keep in contact with management at both of these sites. However, because Treasurer's House was

closed for so long, most of their staff were furloughed and therefore unavailable to answer any of my enquiries, and this lack of response carried on even when Treasurer's House did eventually reopen. It is unclear to me whether this was due to the management no longer being interested in participating in my research or because the management had changed over the course of the pandemic. Whatever the reason, I have very limited data regarding Treasurer's House in comparison with Abbey House and Barley Hall in the context of COVID-19. Given the sprawling structure of National Trust, Heather was unable to provide me with any contact details of Treasurer's House aside from the details I already had.

To collect data about the COVID-related accessibility changes, I surveyed the websites for each case study site and visited each site to see the changes for myself in June and July of 2021. As mentioned, Teagan reached out and offered to visit Barley Hall with me in order to give her perspective on the changes to their site. I did not ask any other participants to join me on my site visits as discussed in section 7.2 above. In addition to my site visits, I interviewed staff members at Abbey House and Barley Hall regarding their COVID-related accessibility changes. I then conducted structured interviews with management staff at Abbey House and Barley Hall via email regarding these changes but also how they expect to re-adapt as the pandemic progresses and potentially ends. The questions I asked them can be found in Appendix F, as well as my field notes from these interviews.

### 7.5.1. Dissemination of COVID-19 Information.

All three sites provide COVID-19 information on their websites, but the presentation of the information varies. On the Abbey House website, they have added a link in the main banner to a separate page containing information regarding new COVID-19 measures. These measures include reduced hours and suggestions for pre-booking tickets. There is also further guidance on mask wearing, social distancing, hand sanitising, and track and trace information, which I further explain in 7.5.2 below. The text is all fairly standard and nondescript; there is little to suggest this is any different than any other museum or heritage site. Indeed, looking at the websites for other venues in the Leeds Museums and Galleries group, the wording is identical (Leeds Museums and Galleries 2021a). A consistent message across all the LMG venues is helpful to visitors, as it creates a consistent branding for the group.

However, the identical wording also suggests a generalisation of the information, that it is not tailored specifically for Abbey House. Surely there are adaptations to Abbey House that are not relevant to, for example, Leeds City Museum, another museum in the LMG portfolio that is housed in a purpose-built building in Leeds City Centre. The two buildings are vastly different, as are the collections housed within. Leeds City Museum is a more traditional "white box" museum of natural history whereas Abbey House is an experiential museum dedicated to the social history of the 19th century. Based on my own experience of white box museums vs experiential museums, I find it difficult to believe that a blanket statement regarding COVID-19 measures could adequately describe the changes at either site.

On the Barley Hall website, their COVID-19 measures are explained in great detail. Where Abbey House is brief and succinct, almost to the point of overgeneralization, Barley Hall is detailed and thorough. A case could be made that it is overly thorough, but research into accessibility has shown that it is better to provide as much information as possible so that people are better equipped to make decisions for themselves (Fisher 2017) and indeed, Principle 4 of the Seven Principles makes this same point (UK Disability Arts Alliance 2021a). The COVID-19 measures they discuss include limited visitor numbers, mandatory mask wearing unless exempt, temperature checks upon entry, pre-booking timed entries, Track and Trace information, one-way system, social distancing guidance, and even a mention that the toilets now have one-touch taps, meaning that the taps turn off automatically and visitors do not need to touch them again once they have washed their hands. There is also an interesting addition at the end of the information regarding staff: "Our staff are ready to help. Barley Hall staff are trained to uphold our safety procedures and will be happy to answer any questions or note any suggestions you have" (The JORVIK Group 2021b). As well as textual information on the website, there is a subtitled video explaining and demonstrating the new COVID-19 measures. Although she did not necessarily find the subtitles helpful, Teagan did appreciate the audio-visual presentation of the information (Appendix D 8.3).

For Treasurer's House, their website primarily lists what visitors can expect from the new guided tour format compared to the previous free-flow style of visit, as well as

how to book tickets (National Trust 2021e). However, they do mention the QR code for Track and Trace as well as the suggestion to pre-book tickets. Additionally, there is a link to an FAQ page at the bottom of the website. The FAQ is relevant to all National Trust properties, not just Treasurer's House, and again, it primarily answers questions regarding ticketing and car parks(National Trust 2021f). As with Abbey House, the lack of details in the description makes me question how adequate this information is for disabled visitors trying to determine if they can visit or not. Indeed, when I showed Teagan this information, she commented that it seemed like the standard information everyone was sharing and that it told her little about what to actually expect if she visited (Appendix C 8.4).

### 7.5.2. New COVID-19 Measures.

As a requirement for reopening, all three sites have installed signs with Track and Trace QR codes for people to "check in" at a site. These QR codes are placed near the entrance for visitors to scan in the NHS Track and Trace app (UK Health Security Agency 2021). This app was created to "track and trace" exposure to the COVID-19 virus, and will alert users if they have been exposed and therefore need to isolate themselves from others in order to prevent spreading the virus further. The app was designed to replace manual entry of names and phone numbers, a legal requirement for businesses to aid in tracing COVID-19 virus exposure (UK Health Security Agency 2021). If a person cannot use the QR code, their details are still taken manually.

Additionally, transparent screens have been installed in the admissions and shop areas at all three sites, creating an extra barrier between staff and visitors to reduce transmission of the virus. These screens have become ubiquitous across all businesses during the time of the pandemic, and many people – staff and customers alike – have found them reassuring as a safety measure (Untaru and Han 2021). On the other hand, many have also found them a barrier to communication. Jess, a staff member at Barley Hall, revealed to me that if the light hits the screen at a particular angle, the screen becomes reflective, making it difficult for visitors and staff to see each other as they interact (Appendix G 2.1).

Perhaps most significantly, all three sites have now instituted caps on how many visitors may be inside at a given time to aid in social distancing. At Abbey House, there is a maximum of 36 visitors allowed in the building at a time, whilst at Barley Hall only eight visitors are allowed in every 30 minutes. At Treasurer's House, only five visitors may book onto a tour slot, with tours running every 15 minutes. Interestingly, the limited visitor numbers are a change that staff at both Abbey House and Barley Hall approved of. George, a front of house staff member at Barley Hall, said the limited numbers make the site feel more like a "home" – appropriately, as the site is styled as a medieval townhouse (Appendix G 2.1). Likewise, Dannie, a front of house staff member at Abbey House, appreciated how the limited numbers meant the crowds are easy to manage, as the site can be very busy one hour and very quiet the next. She told me that the number cap – and the new booking system – help to even out the flow of visitors to make the site pleasantly busy more consistently (Appendix G 1.1). As mentioned above, I was unable to complement this information with interviews of staff members at Treasurer's House in an effort to understand how they felt about the COVID-19 changes to the property.

In addition to the above changes, a new position has been added at Abbey House: a staff member is positioned at the front door to greet visitors, track the number of people in and out of the building, and also to ask visitors to scan the Track and Trace QR code. Staff members actually praised this position, saying that it is an excellent welcome to the museum. An additional staff member at the entrance also means that visitors have an immediate point of contact in the museum instead of winding their way through the shop before being greeted by a staff member. A one-way system through the museum has also been introduced, particularly noticeable in the Victorian street, and signs are placed to show the path for visitors to follow as evidenced in Figure 9.

*Figure 9. A sign at Abbey House showing the visitor route.*

Like Abbey House, a new one-way system has been instituted in Barley Hall to facilitate social distancing. In the original design, visitors essentially double-backed on themselves, retracing their steps to leave the way they came in. Obviously, this is the opposite of a one-way system, and a separate exit needed to be opened in order to allow the proper flow of visitors. To do this, an external door to the Greater Chamber has been opened, meaning that visitors now exit in a completely different way than they had previously, shown Figure 10.

*Figure 10. The door at Barley Hall that now is used as an exit for visitors.*

To assist with the one-way system, Barley Hall has also introduced a handheld map, pictured in Figure 11 below, to show visitors the layout of the building as well as the flow of the one-way system. In discussing the map with Teagan (Abbey House; dyslexia, EDS), she said that overall, the design was accessible for her. It is simple and clear, easy to follow, and it did a good job of helping a visitor orient themselves in an otherwise very complexly laid out and confusing building. However, she did point out that the mix of white-on-black text and black-on-white text is difficult for her to read, as her eyes and brain had to adjust between the two, causing her to slow down her reading. According to the British Dyslexia Association (2021), dark text on a light (but not white) background is preferred. The maps are available to every visitor that enters, and there is also a basket upstairs near the exit for people to deposit maps if they do not want to keep them. The maps are then re-used, after a mandatory quarantine, offering the site an opportunity to be environmentally conscious whilst also providing a useful tool to visitors.
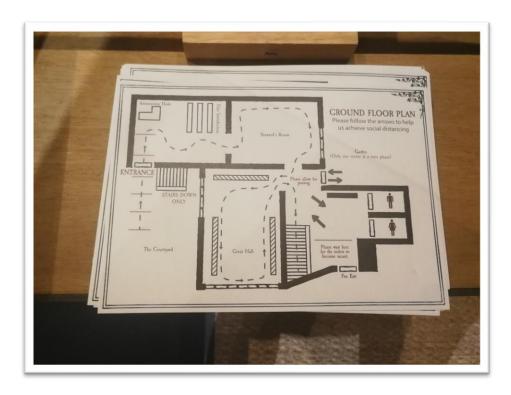
*Figure 11. The new map of Barley Hall.*

At the Treasurer's House, the experience has changed significantly with the introduction of guided tours through the property. At the end of 2019, Treasurer's House was starting to introduce guided tours of the House during the weekdays, using them as a test pilot to see how visitors liked them. Neither myself nor my participants ever went on one of these tours, as front of house and management staff members alike saw these tours as something that was several years off from being implemented, if they were to move to guided tours at all. However, now that they have reopened, there is no more free flow experience and only guided tours are available, a change that seems to now be standard across the rest of the Trust's "Little Gem" properties.

Running every 15 minutes and lasting for about an hour, each tour was led by a volunteer tour guide and had space for only five visitors. Given my decision to not risk exposure of my participants to COVID-19, discussed in 7.2 above, I therefore went by myself. The tour itself was highly structured, and because of how close together the tours started, there was little opportunity to linger in each room. The tour guide did ask the group if they had any questions, but no one on my tour asked any questions or offered any feedback during the tour (Appendix G 3.1).

### 7.5.3. Alterations Due to COVID-19.

Having considered the measures that have been introduced at each of my case study sites, I now consider previous elements of the visitor experience that have been altered or removed at each site. These are important to consider in order to establish how these sites have changed from what my participants experienced.

At Abbey House, all of the interactive elements of the museum – such as colouring and craft activities, objects that visitors can handle, and even the children's soft play area – have been taken away to reduce common touch points in the museum. Instead, craft packs are available, which are pre-made bags of colouring sheets, activity pages, and other small items that would have previously been available on craft tables. One of the "rest" jobs for various staff members now is to make these bags, meaning that if the museum is quiet, they have implicit permission to work on these and do not need to seek permission from their manager.

Much of the first floor is also closed off, as social distancing cannot be maintained nor can a suitable one-way system be instituted. This includes the Gallery of Childhood, which features toys from the Victorian period through to the present. Staff members expressed disappointment but also understanding about this decision, saying that it was a very popular exhibition, especially with young visitors (Appendix G 1.1).

At Barley Hall, the introduction of the one-way system has meant that some of the exhibits had to be adapted and, in some cases, moved entirely. The entrance area now is no longer a combined admissions and shop area, but instead an admissions area with a curtained off area with benches for visitors to sit on as they watch an 8-minute subtitled video introducing the site and providing relevant context about the setting of the townhouse. This video used to be positioned in the next room, the Steward's Room, which itself has had a slight re-arrange. With the absence of the video, the Steward's Room now has a subtly guided path for visitors to follow, immersing them in the medieval experience immediately. The absence of the video also means the Steward's Room is less noisy, meaning there is less distraction as people read the text panels in the room.

Upstairs, the Greater Chamber has been turned into a gift shop, shown in Figure 12 below, where a second member of staff is now positioned. This is also where the new exit is – to be clear, the door always existed, as did the external staircase, but it had been closed off from public use and was generally only used by staff to quickly enter and exit the adjacent office area. The exhibition that was originally in the Greater Chamber has been moved to the Study, which before was fairly empty. Additionally, the Schoolroom, Buttery, and Pantry have been closed off entirely, as the areas are too small to ensure social distancing.



*Figure 12. The Greater Chamber in Barley Hall now holds a gift shop and the exit to the building.*

Like Abbey House, Barley Hall has removed as many interactive elements as they can, especially those activities aimed at children. In the Gallery, there was a wand-making craft where children would decorate sticks with ribbons and gem stickers. As Paul T pointed out, it was "a communal activity and encouraged interaction between visitor groups" (Appendix G 2.1). In its place, visitors can now book or ask for a free crafting pack which includes all the materials needed to decorate a "wand." There also used to be a stamping activity where visitors could pick up a free booklet at the admissions desk and stamp pages in their booklet at stations located throughout the

museum. Unfortunately, there is no alternative for this, so the activity has been pulled entirely. There are also signs that ask people not to touch items.

In addition to the interactive elements in the exhibition, the sensory packs, discussed in Chapter 6, were initially taken out of circulation, as the yellow backpacks they came in were difficult to sanitise due to their material. This was an understandable measure at first, especially as there was limited time to think of alternatives. However, as more time passed, the decision was revisited and it was determined that although the yellow backpack was difficult to sanitise, an alternative case could be found and cleaning procedures put in place. At Barley Hall, the yellow bags have been replaced with hard plastic tool boxes that can be easily wiped down with a sanitising cloth, shown in Figure 13 below. All the objects inside can similarly be wiped down, and the sensory pack is also put in isolation for three days – guaranteeing that any potential COVID-19 virus on the pack and its contents are gone before the pack is used by another visitor.



*Figure 13. The new sensory pack at Barley Hall in its hard plastic tool box.*

As at Abbey House, the staff members commented that the experience has changed drastically. Gwen said that she has seen families with smaller children spend about 5-10 minutes in the building before leaving again, whereas they could spend all day in the museum before (Appendix G 2.1). Without the interactive elements, there is

little to hold a young child's attention, and this is something Jess was deeply disappointed in (Appendix G 2.1). There have been no complaints that she was aware of, as most visitors are understanding that the pandemic has forced certain changes, but she is looking forward to when those interactive elements are brought back. It seemed to Gwen that once the pandemic had subsided, or at least once restrictions were relaxed, these interactive elements would return.

As with the other sites, any interactive elements that existed at Treasurer's House before the pandemic are now absent. Personal interpretation boards, discussed further in Chapter 8, are nowhere to be found, and the tablets that room guides had been promised, discussed Chapter 6, are also absent. The only addition in any room are some black chairs, ones that are available for people to sit in should they need it during the tour, shown in Figure 14.
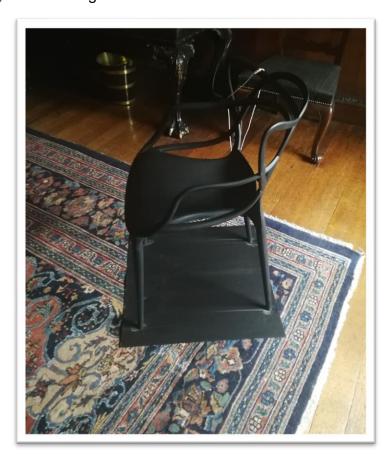


*Figure 14. A black plastic chair in a room at Treasurer's House.*

## 7.6. Discussion.

In examining the changes and alterations that have taken place at each case study site, it is not readily apparent how the overall accessibility of the sites have been

impacted. Indeed, I argue that accessibility both increased and decreased at the sites, which I discuss further below.

In looking at the dissemination of relevant COVID-19 information, all three sites include text on their website, but Barley Hall has an additional, subtitled video explaining these changes. By using a video, Barley Hall includes an additional layer of accessibility into their information, allowing people with text-related disabilities (dyslexia, Irlen Syndrome, low vision, etc.) to still access the information. The subtitles, too, ensure that people with hearing difficulties can understand what is being said in the video. Additionally, the video shows the various new measures in context, even including demonstrations of how to interact with these elements. Again, this adds other layers of accessibility to the content, showing people who have social interaction difficulties (anxiety, autism, etc.) what is expected of them. As mentioned in Chapter 6, Barley Hall offers visual/social stories for the same reason: to allow people with social interaction difficulties to feel more comfortable during their visit, without an overwhelming experience of "newness" making their visit uncomfortable. Maggie, a senior management staff member the JORVIK Group, explained to me in an interview that the video had been created with accessibility in mind, specifically to be a visual/social story in video form. She also expressed a desire to produce more videos like this in the future for the other sites within the JORVIK Group, but instead of focusing on COVID-19 measures, these future videos would introduce each site more generally. In this regard, the pandemic has encouraged Barley Hall to reconsider how they communicate with visitors and find more accessible options. I discuss in Chapter 10 how Barley Hall management is particularly committed to accessibility, and this video further demonstrates such commitment.

The introduction of one-way systems at Abbey House and Barley Hall, in my opinion, have also had positive impacts on the accessibility of their sites. As will be discussed further in Chapter 8, participants at both sites found the original layout of the buildings confusing. The newly introduced one-way systems, complete with signs or maps, lay out a definitive path for visitors to follow. At Treasurer's House, the change to guided tours has, in my opinion, likewise solved its issues with layout. Participants found the original layout confusing whilst staff members bemoaned how visitors

would often become lost within the property (see Chapter 8). But now that all visitors are led by a tour guide throughout the property, it seems there is far less confusion. Again, the pandemic has unintentionally increased the accessibility of these sites through the introduction of new measures.

Limiting visitor numbers at all three sites has also been a boon to accessibility. Before the pandemic, it was common for places to engage in special events like "Autism Hour," where numbers were restricted and various sensory inputs, like sounds and variable lights, were turned off in an effort to be more "autism friendly" (National Autistic Society 2021). Although sites have not necessarily adjusted the sensory inputs of their exhibitions for the pandemic, the limited admission numbers are critical to a more inclusive museum environment. With fewer visitors inside a building at a time, there is less crowding and less overall noise, meaning that people with sensory difficulties have less sensory input and are more likely to enjoy their visit (Museums + Heritage Advisor 2021a). Interestingly, one participant, Lisa (Abbey House; anxiety), shared with me that she preferred to visit museums during their less busy times, as she could avoid large crowds (Appendix C 9.4). Indeed, during our visit to Abbey House, she avoided areas where there were other groups of visitors. When I asked her if she would attend advertised "autism hour" events or even "quiet hour" events, she said that she would not, as she "wouldn't feel it was for me… I feel like if there's something that is for autism, then those people with their carers or their families should be able to enjoy that and not feel like they have to share that space and be apologetic for outbursts like that so that's just me being in that they deserve that. That's their time and space" (Appendix C 9.3). Lisa's hesitancy to use an accessibility tool, even one she would find helpful due to her disability, presents an interesting conundrum. On one hand, she would benefit from attending these quiet hours. On the other hand, she does not identify as autistic or even disabled (Appendix C 9.4), and is therefore reluctant to take away accessibility tools from people who "deserve" them. But the introduction of caps on the total number of visitors at sites resolves this tension. There is no need to advertise quiet hours, as the limited numbers mean that every time slot is a quiet time. Yet again, the COVID-19 adaptations answered an accessibility need that had been overlooked up to that point.

At each case study site, there are individual adjustments that have added to the accessibility of their site. At Abbey House, the introduction of the new staff position at the door has been heralded as a good thing by other staff members, and I argue it is a good thing for accessibility too. Although I had limited opportunity to observe staff members in the role, there is a great amount of potential in having a staff member location there. Before the pandemic, the first staff member that a visitor encountered was stationed on the opposite end of the shop. In order to approach the staff member, a visitor had to wind their way through tables and product displays, something that could be difficult for a visitor with mobility problems, wheelchair users, and even visitors with pushchairs. Indeed, Teagan, who had a pushchair with her when we visited Abbey House, commented that "if I had anything wider than [her pushchair], I wouldn't be able to get around" (Appendix C 8.2). Teagan's observation shows that the layout of the shop itself is a barrier to some visitors, meaning they must turn back before they even speak with a staff member. However, with a staff member positioned at the door, not only can they greet visitors and assist them in using the Track and Trace app, but they can also speak to disabled visitors about their accessibility needs. During my staff interviews at Abbey House, it was clear that front of house staff members are well-versed in the accessibility tools available at the site, as well as the barriers of the site. The latter is important, as this information will allow a disabled person to decide for themselves whether they can access the museum or not.

Additionally, given the generality of the COVID-19 information on the Abbey House website that I discussed in 7.5.1 above, the staff member at the door can provide more detailed information about the COVID-19 measures throughout the museum, again allowing the visitor to choose for themselves whether they are able to access the site. Likewise, the potential visitor can also ask questions of the staff member, clarifying any information that may have been confusing or vague on the website. The staff member can also offer one-on-one assistance to disabled visitors – although I did not witness this myself, two staff members at Abbey House excitedly shared with me an encounter they had the day previously with a visitor who had visual difficulties (Appendix G 1.1). The staff member on the door provided personal assistance to the visitor, guiding her through the shop which otherwise would have been difficult for her to traverse. The new staff position at the door may have been

introduced as a COVID-19 measure, but it has also increased the accessibility of Abbey House.

At Barley Hall, the rearrangement of some of the exhibition has proved to be an unexpected boon for accessibility. As described above in 7.5.3, the Steward's Room in particular was altered, with the removal of a video and the rearrangement of some furniture, particularly a table placed midway into the room to subtly guide visitors around the room, shown below in Figure 15. Not only does the removal of the video mean that visitors are immediately immersed in the medieval setting once they cross the threshold into the room, but there is also a marked difference in the noise levels in the room. Indeed, in relistening to the audio from my site visit with Alfie (Barley Hall; dyslexia, monocular vision), the video is so loud that I cannot understand what we are saying to each other (Appendix C 2.2), despite being closer to the microphone than the video speakers. As with the numbers cap above, this lessened sensory input means that neurodivergent visitors may have an easier time focusing on the interpretation in the room – particularly, the wall-mounted text panels that hang next to where the video originally played.
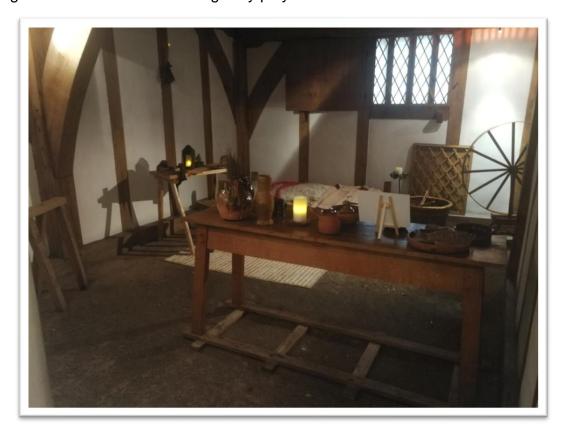


*Figure 15. The new layout of the Steward's Room at Barley Hall.*

At Treasurer's House, chairs have been added to each room for visitors to sit in, should they need to sit during their tour. I discuss seating through the lens of communication in Chapter 8, but here I wish to expand upon the importance of these chairs. In visiting Treasurer's House, many participants noted that there were not enough places to sit – or more specifically, it was difficult to understand where they could sit and where they could not (Appendix C 1.3; 4.3; 5.3; 6.3; 7.3). Multiple chairs, benches, and couches are present in each room of Treasurer's House, but it is not always clear which chairs are part of the collection and which are for visitors to sit in. As Amy put it: "There are actually loads of places to sit, they're just labelled so badly" (Appendix C 4.3). As an example, in one room, there are two nearly identical chairs next to each other, shown below in Figure 16 – one is part of the collection, whilst the other is a chair that visitors can use. Additionally, nearly every participant, regardless of the site they visited or their disability, needed to sit and rest at some point during our visit (Appendix D 3.3; 4.3; 5.3; 6.3; 7.3; 8.3). Not being able to discern which chair they can sit in is almost as frustrating as having no seating at all, according to my participants.



*Figure 16. Two extremely similar chairs in a room at Treasurer's House. The chair on the left is part of the collection and cannot be touched. The chair on the right is for visitors to sit in.*

The introduction, then, of these new chairs to Treasurer's House is a bonus for disabled visitors. Shown below Figure 17, these chairs are clearly not part of the collection, as they are made of sturdy black plastic and are placed on black stands,

presumably to conserve the flooring beneath the chair. One of these chairs stands in each room, meaning that there is always an obvious place for visitors to sit during their guided tour, no matter where they are in the property.
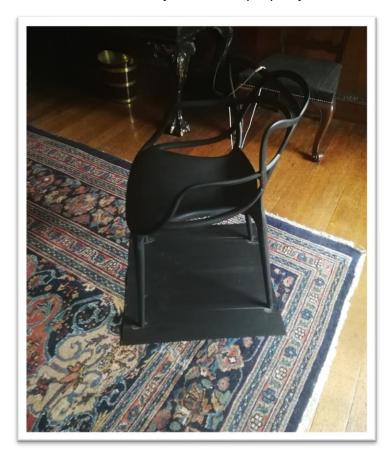


*Figure 17. A black plastic chair now found in Treasurer's House.*

However, James (Treasurer's House; fibromyalgia) makes a salient point when he says "on a busy day in general, because [it is] the sort of attraction that would attract the older person who may need to sit down a bit more...I would say that there probably wouldn't be enough seats" (Appendix C 6.3). At the moment, only five people are allowed on a tour at a time – but given that nearly 20% of the UK population has a disability (Office for National Statistics 2015), it is almost guaranteed that one visitor on any given tour will have some kind of disability. Additionally, older people are more likely to have disabilities as part of the aging process (Buhalis et al. 2012), and as James rightly points out, the visitor demographics of Treasurer's House – and the National Trust more widely – tend to skew older. Therefore, it is not unrealistic to assume that more than one person on a tour could benefit from using a chair. As I was unable to speak to anyone at

Treasurer's House regarding the decision to include these chairs, I can only speculate as to why they only keep one chair in each room. The size of the rooms is not prohibitive to more chairs, but given the number of rooms in Treasurer's House, perhaps cost is a consideration. Visitors are guided through at least ten rooms in the property, so filling these rooms with chairs could be costly, but I do not find this an adequate excuse. In speaking with my supervisor about this, she commented that she would not feel comfortable sitting down if there was only a single chair – echoing Lisa's statement about not wanting to take something away from someone who needs it more. Indeed, as I went around on my guided tour, I was hesitant to use the chair, despite feeling tired after being led through the property and traversing up and down two staircases. I was the youngest member of the tour and did not want to deprive my older tour members, one of whom walked with a cane, the chance to rest. All of this is to say that the property would benefit from having more than one chair in each room for visitors to use, but the fact that they have added these chairs in the first place is a bonus for the accessibility of their site.

Despite all the positive impacts on accessibility that took place at my case study sites due to the pandemic, there are significant negative impacts as well. Most obvious is the removal of all interactive media from the sites, citing the need to keep touch points to a minimum to prevent the spread of germs and the virus. At Abbey House, crafting activities, handheld interpretation text, and objects to handle have all been removed. At Barley Hall, crafting activities have been removed and signs have been placed asking people to not handle objects. As an additional blow, the sensory packs, which had been designed specifically with accessibility in mind, were taken out of circulation. At Treasurer's House, the personal interpretation boards have been removed, as well as the visual aids that room guides previously used, such as oversized photos and objects that can be handled. Staff members at both Abbey House and Barley Hall mourned this particular loss (Appendix G 1.1; 2.1). Both Abbey House and Barley Hall sell themselves as immersive experiences, and to take away the interactive elements takes away from that immersion. Multiple studies have shown that these interactive elements not only add to the overall museum experience, but also increase learning and engagement (e.g., Pallud 2017; Haywood and Cairns 2006; Feher 1990).

Not only that, but also the co-presence of others engaged in the same activity is a particularly powerful aspect of the interactive experience. Haywood and Cairns, in developing a hypothesis for why interactive exhibitions are so effective for learning and engagement, noticed the importance of co-presence (2006, 10-12). Their research was centred around children's engagement and learning at a science museum, but their findings are equally relevant to my case study sites, as they frame interactive elements of their exhibits as important to learning and engagement. It should be noted that there is an important distinction between co-presence and collaboration. As Haywood and Cairns (2006, 11) noted, "it emerged that in order to adequately conceptualise children's experience with interactive exhibits it is essential to consider the co-presence of others." The importance of co-presence is something that staff members commented upon. Gilly (a front of house staff member at Abbey House), in reflecting upon where the crafting table used to be located in Abbey House, said that she loved watching children interact with each other and noted that the children enjoyed it as well (Appendix G 1.1). Paul T (a front of house staff member at Barley Hall) too commented that the wand-making craft activity in particular became a communal activity and encouraged interaction between different visitor groups (Appendix G 2.1). Without these interactive activities, there is no scope for interaction between groups – and therefore, limited potential for significant learning and engagement, particularly for younger visitors.

Additionally, studies have also found these interactive elements to be key in terms of accessibility (e.g., Allen and Minnion 2020; Shepherd 2009). McMillen (2015, 101), for example, discusses the impact of relief printed media that transforms 2D images into 3D, textured prints for people to touch. She points to these prints as useful for blind visitors, but I posit that the tactile element of these prints is useful for a much wider disabled audience, particularly for neurodiverse visitors who learn best through touch. Indeed, Eardley et al. agree (2016, 265), saying "the provision of multisensory information could enhance the learning opportunity for all visitors." In their research, they examine memorability through interactive elements specifically designed for disabled visitors. They found that (2016, 283):

> If these museums were both attempting to redefine (dis)ability by producing an
> experience that could be shared and experienced in a way defined by each individual

visitor, by providing information through multisensory means, they are potentially also improving the long term memory or impact of the museum visit for all visitors. Not only did these multisensory, interactive elements increase accessibility for disabled visitors, these same elements also increased memorability for all visitors, disabled and nondisabled alike.

Likewise, the removal of the personal interpretation boards from Treasurer's House has negatively impacted the accessibility of the property. Moreover, the design of the tour in general, I believe, has negatively impacted accessibility. The tour is delivered orally, meaning that visitors like Jessica (Treasurer's House; dyslexia, Irlen syndrome) and Alfie (Barley Hall; dyslexia, monocular vision) need not worry about reading text panels, which they find difficult (Appendix C 2.3; 7.3). However, d/Deaf people or people with hearing difficulties, attention issues (such as Kasi with her ADHD), or audio processing difficulties (a side effect of OCD, which Aaron and Amy both have) may struggle to engage with the oral transmission. Additionally, several participants mentioned during their interviews that walking at a pace different from their own was physically painful. Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) shared that "walking solidly for 20 minutes wouldn't have as big an impact as if I was walking for five minutes, stopping for 10 minutes" (Appendix C 5.4). Echoing Ellie's statement, Amy (Treasurer's House; anxiety, hypermobility, OCD) told me "I have to go at the speed that I go, if that makes sense. And slowing down and speeding up is painful" (Appendix C 4.3). The enforced stop-and-start pace of the guided tours would therefore likely become a barrier to Ellie and Amy's physical comfort if they joined one of these tours, even to the point of causing physical pain in them.

Discussed further in Chapter 8, the appeal for my participants of the personal interpretation boards at Treasurer's House was their capacity to be tailored to the personal interests of whomever picked the board up. Three different themes were discussed in each room, so visitors could pick and choose what they wanted to learn about. Additionally, they provided written textual information for people who prefer reading. Visitors using the boards could also spend as much time with them as they liked, meaning they could walk at their own pace around the room with the boards, as Amy and Ellie above mention. Visitors with reading difficulties, such as Alfie

216

(Barley Hall; dyslexia, monocular vision), Jessica (Treasurer's House; dyslexia, Irlen syndrome), Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS), and Teagan (Abbey House; dyslexia, EDS), could take their time reading them or bypass them altogether. The key to these boards was the flexibility they offered to visitors, something that is completely stripped away in the Treasurer's House guided tour as I experienced it. As discussed above in section 7.5.2, the structure of the new tour was highly rigid and did not allow for much flexibility or personalisation.

Taking all these adjustments together, I am struck by the fact that many of the changes that have negatively impacted accessibility are also the changes that staff members are keener to see reversed. The removal of interactive elements has been universally seen as a negative – but necessary – move in the eyes of staff members at my case study sites. However, in my interviews with Maggie (Barley Hall) and Mary (Abbey House), they both expressed the desire for the interactive elements of their sites to return as soon as it is deemed safe. At Barley Hall, they also now intend to keep the new layout, although they will be less strict on the "one-way" aspect of it once pandemic restrictions have been lifted. They likewise intend to keep the maps to guide visitors around the site. The accessibility of these three sites has been altered, and sometimes negatively so, but the pandemic restrictions have also provided numerous opportunities for improved accessibility that can remain in place even after the pandemic.

## 7.7. Summary.

Throughout this chapter, I have focused on the impact of COVID-19 on the disabled community, particularly people with hidden disabilities. It is not a stretch to say that they have been unduly impacted by the changes that the world – and the heritage sector more specifically – has undergone. In many ways, my case study sites have used the pandemic, sometimes unintentionally, to increase the accessibility of their sites, although they have also necessarily had to decrease accessibility in certain areas at the same time. Whereas the original COVID-19 changes were decided and implemented without input from visitors or staff members, my case study organisations have now had the opportunity to listen to feedback and to act accordingly upon it as they did at Barley Hall. As the world continues to adjust to the

ongoing pandemic, these measures will likewise need to adjust, and by listening to disabled visitors, my case study sites can ensure a more inclusive visit for everyone.

# Chapter 8 – Active vs Passive Accessibility.

"Oh, I really like these!" Amy (anxiety, hypermobility, OCD) whispers as we walk around the West Sitting Room of the Treasurer's House. Compared to other rooms in the house, it's rather small, almost intimate in size – except for the giant fireplace that takes up nearly an entire wall. But it's not the fireplace that Amy is commenting on, it's a set of ebony wood chairs with small inlaid eyes along the back, shown in Figure 18. It's exactly the kind of quirky thing that Amy would have in her home. "Can you just imagine? People leaving a dinner party and all they keep saying is 'the chairs have eyes!'"
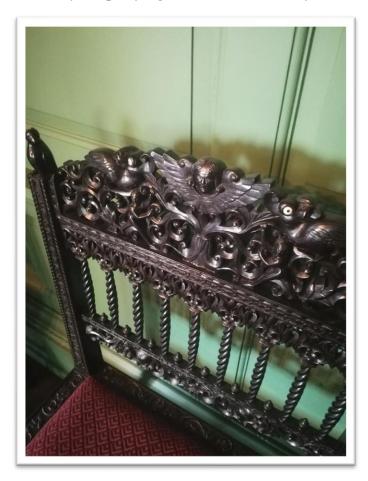


*Figure 18. An ebony wood chair with ivory inlaid eyes at Treasurer's House.*

As we chat further, Amy comments that she's not sure if she could touch the chairs themselves, just to see what the eyes felt like. This is, after all, the National Trust, where everything is on open display but there's still an air of "do not touch" hanging over everything. Amy would rather not risk the ire of the room guides by touching and potentially damaging a priceless, one of a kind artefact.

"They actually just introduced a touch tour," I offer. As someone who also has anxiety, I fully understand her concern. Most people understand museum admonitions to stay hands off as a conservation concern, which it primarily is. One person touching an object for a split second may not damage the item, but if every visitor touches the object, however delicately, it will become damaged over time. To a person with anxiety, though, it doesn't matter that it is this build-up of handling that damages the object. An anxious brain automatically goes to the worst possible case, no matter how ridiculous. In the case of our chair, Amy is worried that if she touches the chair, it will instantly crumble into dust and she'll receive a life-long ban from all National Trust properties. To be clear, every part of Amy's scenario would not happen, but that doesn't matter to her brain. Anxiety takes this extremely unlikely, worst-case scenario and turns it into an absolute certainty.

"Oh really? Where is it?" Amy looks delighted by the opportunity to actually touch historical objects.

"They keep it on the reception desk – you just have to ask for it."

"Oh." Amy's face immediately falls. I ask her why she has that reaction. "I just hate asking for things. I don't want to bother anyone."

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Amy's dislike of requesting things perfectly exemplifies a large problem surrounding accessibility tools: people have to ask for them. Large print guides, braille guides, transcripts, magnifying glasses – these are all small, easily created or purchased items that are often kept behind the admissions desks at museums. By making visitors request these accessibility tools, rather than embedding them within the design of an exhibition, sites have turned these tools into an "active" accessibility measure.

The notion of active and passive accessibility is still finding its roots in disability studies, but it is a long-standing concept in the world of transportation (e.g., Coppola and Silvestri 2018; Lättman et al. 2018; Cascetta et al. 2016, 2013). Simply put, active accessibility describes an individual moving from zone to zone in order to achieve a particular goal, while passive accessibility describes the amount of opportunities (or hindrances) to achieve a goal in a particular place. Active accessibility is person based, while passive accessibility is location based.

When these concepts are transferred to disability studies, active accessibility can be seen as a disabled individual navigating barriers as they go about their lives. For example, someone with arthritis may have to navigate stairs, curbs, and crowded shelves in order to cross the street and buy some milk from the corner shop. Passive accessibility, on the other hand, describes the various methods of buying that same carton of milk. The person with arthritis can choose between stairs or a lift, between going to the shop or ringing a friend up to get it for them, or even ordering the milk online to have it delivered to their door.

Active vs passive accessibility also has parallels in the medical and social models of disability, which I discuss more thoroughly in Chapter 1. In the medical model, which focuses on the 'deficiencies' of an individual, a disabled person has to adapt to the world. Active accessibility echoes this, as it focuses on the individual moving through the world. The social model of disability, however, highlights how society creates unequal opportunities and therefore disables a person. Likewise, passive accessibility concentrates on the environment and how it helps or hinders a person.

In terms of museums and heritage, active and passive accessibility are useful concepts; however, it is slightly more complicated than person-focused or place-focused. Museum experiences are, by their very nature, both person-focused and place-focused. It is arguably the combination of a person in a specific place that allows the museum experience to arise. Admittedly, work is being done on off-site virtual heritage experiences and became increasingly popular during the COVID-19 pandemic (Kist 2020; Samaroudi et al. 2020), but for the sake of my research, I focus on in-person museum visits, and therefore, the interaction between people in a specific place. Active and passive accessibility must then be understood in terms other than person-focused and place-focused.

I divide active and passive accessibility in terms of gatekeeping: if a visitor must ask for something, such as the touch tour mentioned in the vignette above, this act of asking represents a form of active accessibility. Examples of such active accessibility include temporary ramps that must be put up or taken down by a staff member, or a Braille guide that is kept behind the admissions desk. Passive accessibility tools, on the other hand, are either built into the exhibition design, such as dyslexia-friendly fonts or automatic subtitles on videos, or out in the open for anyone to use, such as a bench to sit on or an automatically opening door.

I argued in Chapter 1 that both the medical and social models of disability have their uses. I likewise argue that both active and passive accessibility are useful in museums. There are a number of reasons why a museum may choose to take an inherently neutral tool, like the touch tour, and make it active. For instance, as Ellen from Treasurer's House explains in her interview, they chose to keep the touch tour behind the desk and only give it to people who ask for it in order to limit the damage to these touchable items. Through negotiations with the conservation team, they identified different objects that could be handled on occasion, but they would prefer to err on the side of caution and only allow people access to the tour who, as she put it, would truly benefit from the experience. How they determined who would benefit from the touch tour is left vague and open to interpretation, but they do not want every person walking through the property to touch each of those items. With this in mind, it is clear that sometimes an active accessibility tool is the best compromise between conservation and access, according to a particular organisation.

Although active accessibility certainly has its place in museums, passive accessibility is more helpful overall for visitors. As Amy said above, she dislikes asking people for things, which prevents her from using any of the active accessibility tools a museum may have (Appendix C 4.2). In her case, asking for something is difficult due to her disability. For others, it is a public admission of a disability, one that they may not wish to announce. Additionally, many people may find specific accessibility tools useful, such as ear defenders or visual stories, but the very fact that these tools are labelled as "accessibility tools" prevents them from being used. Some people eschew using them as they do not want to be identified as "disabled." Even amongst my participants, who were selected for their experiences of having a hidden disability, not everyone identified as disabled. Lisa (Abbey House; anxiety), when I asked if she identified as disabled, simply said she did not (Appendix C 9.4), and Amanda (Barley Hall; heart failure, psoriatic arthritis) even noted that her reluctance to use a cane or walker was "a bit of pride in me at the moment" (Appendix C 3.1). It stands to reason that in the wider population, a similar attitude would manifest in a number of people, meaning that they would be reluctant to ask for these accessibility tools regardless of how useful they might find them.

Even for those who do identify as having a disability, they may not wish to take away an accessibility tool from someone who may need it more. Recall in Chapter 7 how Lisa (Abbey House; anxiety) did not want to crowd "quiet hours," understanding them to be primarily focused on autistic visitors and their families (Appendix C 9.3). It should be noted that Lisa herself acknowledged that having fewer people in the museum whilst she visited would have helped her enjoy her visit more, yet she still feels that she should not take away a resource from someone who was "more deserving." Having passive accessibility tools means that more people can utilise them without having to "out" themselves as disabled, without having any stigma attached to using an accessibility tool, and without using up a limited resource that someone else may also benefit from.

This chapter examines three elements that repeatedly proved challenging to my participants during their site visits: layout, lighting, and communal reading. Each of these challenges is explored through a selection of vignettes and quotes from my

participants, as well as observations made during my ethnographic study of the sites and interviews with staff and management from the case study organisations. From there, I discuss passive accessibility measures that have been suggested by my participants and in some cases, introduced at the sites to address these barriers. Finally, I review future plans the sites have regarding these three challenges and potential passive accessibility measures to mitigate them.

## 8.1. Layout.

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"Sorry, which way to the café?"

I'm standing in the entrance hall, off to the side of the reception desk. This is where visitors to the Treasurer's House enter, pay their admission or flash their National Trust membership card, and are welcomed into the site. The room itself dates to the early 17th century, though many of the features of the room were added in subsequent centuries (National Trust 2000, 4). In a way, this room is representative of the Treasurer's House as a whole: a centuries-old space that has changed and adapted over time, complete with a personal Frank Green twist. Green, the famed final owner of the House who gifted it to the National Trust, changed the windows and raised the fireplace, the central feature of the room (National Trust 1978, 10). There are four entrances to the room, though one is blocked off. The visitor asking for directions has just entered from the north-western entrance, marked with a star on the map in Figure 19.
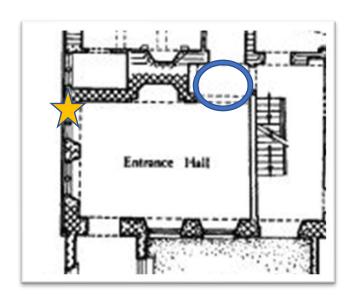
*Figure 19. A map of the admissions area of Treasurer's House (scan taken from National Trust 1978).*

"Oh, it's just this way, down the stairs and through the shop." The admissions staff member, Jay, points to the north-eastern doorway, a doorway which is hidden to the visitor from their position and marked by a circle on the map in Figure 19 above. The host is all smiles as the apologetic if confused visitor heads down the stairs, but once the visitor is out of earshot, they turn to me with an exasperated expression on their face. "That happens ALL the time! We give them directions when they first enter, but either they're not paying attention or they've forgotten or whatever. It's so frustrating!"

To be fair to the lost visitors, Treasurer's House has a confusing layout. Just like the entrance hall, the interior has changed multiple times during its lifetime, and before its current iteration, it was three separate apartments – something that shows in the arrangement of rooms. Curious as to whether the layout really is an issue, I begin my own unofficial observations. I position myself in the Gallery, overlooking the Great Hall where I can watch the action below. In a span of 30 minutes, 24 people came through the Great Hall. Of those 24 people, 7 people ask for directions or clarification on the layout – and

3 of those 7 people have to ask multiple times, as they became turned around and confused again[6].

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Like the visitors above, my participants found the layout of Treasurer's House confusing. Both Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) and Amy (Treasurer's House; anxiety, hypermobility, OCD) mentioned that they would have preferred some kind of suggested route through the House (Appendix C 5.3; 4.3). Although neither specifically mention their anxiety as an underlying cause for this desire for a suggested route, it is interesting to note that they share the condition. The desire for an "official" route was also brought up by another participant, Lisa (Abbey House; anxiety), who did specifically link it to her anxiety: "For someone who has anxiety, it's just not very clear where [I should go]" (Appendix C 9.3). The clarity – or lack thereof – of a path meant that her enjoyment of the visit was overshadowed by the need to make the "right" decision regarding where to go within the museum. Amy (Treasurer's House; anxiety, hypermobility, OCD) echoed this sentiment, saying "I enjoy not having to make any decisions [regarding where to go] and I enjoy [visiting a place] where I can make sure that I see everything that the museum wants me to" (Appendix C 4.3). There is a certain level of comfort in having a prescribed route, one that allows a more relaxed visit for Amy and Ellie and potentially many more visitors to Treasurer's House.

Visitors to Barley Hall encounter a similar issue in the layout of the building. Originally built sometime in the 14th century, Barley Hall has changed from a monastic hostel to a goldsmith's mansion to interconnected dwellings and workshops to its current iteration as an immersive museum (York Archaeological Trust 2011, 6-10). Like Treasurer's House, several disparate and altered apartments were individually bought up and recombined to fit the vision of the building's current owner (York Archaeological Trust 2011, 12; National Trust 1978, 6). The building itself even stretches over a small public right of passage, labelled as "snicket through hall" on

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[6] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

the map, further confusing the arrangement of the building. Also, like Treasurer's House, a visitor must double back through previously visited areas in order to experience the entire museum, as shown in the map below in Figure 20.
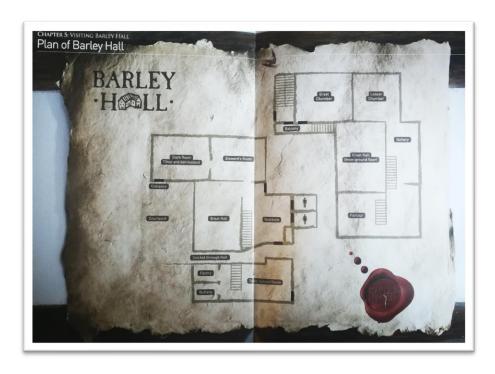


Figure 20. Barley Hall guide map (scan taken from York Archaeological Trust 2011).

Most of my participants want to visit the whole museum during our site visit, and it is understandable that there is frustration regarding the layout of the sites. This is particularly true of Barley Hall, where nearly a third of the building is accessible only by one easily missed doorway, shown in Figure 21 below. Alfie (Barley Hall; dyslexia, monocular vision) and Amanda (Barley Hall; heart failure, psoriatic arthritis) both mention that they nearly missed that entire section of the building, citing the "odd layout" (Alfie – Appendix C 2.3) and how "it didn't flow from one [area] to the other" (Amanda – Appendix C 3.3). A similar problem arises at the other two sites as well: very often, participants are unclear if they have seen the whole museum, as there are no apparent signs or maps to guide them from one area to another.

*Figure 21. The door, indicated by the arrow, nearly missed by my participants leading to another area of Barley Hall.*

To clarify, Barley Hall did offer a map of their site pre-pandemic – however, it is located inside a guidebook that is available for purchase when the visitor pays their admission. None of my Barley Hall participants opts to purchase the guidebook, and Amanda (Barley Hall; heart failure, psoriatic arthritis) points out that she would not have been able to carry the guidebook around with her anyway, due to her disability (Appendix C 3.3). In this sense, there is a gate-keeping aspect to the map. It is only available to people with the fiscal and physical means to purchase and carry the guidebook, which could be construed as discriminatory. Treasurer's House relies on volunteer room guides to answer questions for visitors who may be lost, but room guides at Barley Hall are very rare. Even when they are available, they are generally stationed in the Great Hall or the Gallery, and their primary responsibility is to offer interpretation of that room. Unfortunately, due to the COVID-19 pandemic, I was unable to interview any volunteers at Barley Hall nor was I able to observe them.

Interestingly, Barley Hall does have a wall hanging that could be used as a map of the building on display, shown in Figure 22 below. However, the wall hanging is

located not at the beginning of the museum, but rather in the corner of the second room on the visitor route. It is also not entirely clear that it can be used as a directional diagram, especially since it describes the phasing of the building. None of my participants even notice the wall hanging, let alone use it to clarify their route.
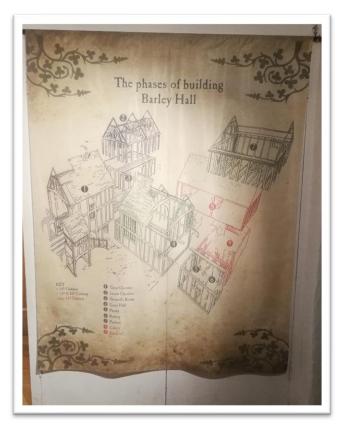


*Figure 22. A wall hanging in Barley Hall that shows the phasing of the building. It could be used as a map of the building.*

Abbey House has a similarly confusing layout. The building includes many phases of construction – the café, for example, dates back to the 12th century when it was the gatehouse for Kirkstall Abbey (Leeds Museums and Galleries 2020a), which now stands across the road, and is also the inspiration for the café's name, the Gatehouse. Other parts of the building have been built in subsequent centuries, and it is clear that this is a converted building, rather than one that is purpose-built to be a museum. In that regard, it is an interesting departure from the other two case study sites. Barley Hall and Treasurer's House are both listed buildings from previous centuries, but the interpretation within each site is related to the century that it was built. Barley Hall is a medieval townhouse and presents itself as such. Treasurer's House was redesigned by Frank Green, and so puts that aspect of its history at the forefront. Abbey House is a mix of different periods, but is primarily focused on 19th century social history. To that end, there is a recreated Victorian Street that takes up

most of the ground floor. Visitors are encouraged to explore the street before they travel to the first level where more traditional, although still immersive, exhibits are housed. However, like many real-life Victorian streets, the exhibit has several smaller alleyways to explore, as well as a number of shops that visitors may enter or travel through to another part of the street. The effect of all these alleyways and shops is that the street as a whole is maze-like, making it very easy for a visitor to get turned around.

This is, in fact, precisely what happened with my participants. Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) has a particularly difficult time finding her way around in general, saying "I lose direction very easily and don't have the best spatial awareness. This can mean that without a map I either get lost or have no idea where I have or have not been in an area" (Appendix C 8.3) Teagan (Abbey House; dyslexia, EDS) echoes that sentiment: "Without the maps [being available], I think we weren't able to target places we wanted to see as well" (Appendix C 8.3). In an earlier interview, Teagan mentions that, because of their EDS, it is very important to her and Kasi to sort of 'pre-plan' their visit, making a note of which exhibits they want to see most (Appendix C 8.1). They have limited amounts of energy, as well as limited mobility, so prioritising exhibits is a necessity for them to have a successful visit. Without a map being available, they are unsure not only which exhibits are available, but which ones they want to see the most.

A lack of directions also means that visitors rely on interaction with staff members to receive directions. As highlighted in Amy's vignette at the very beginning of this chapter, many people feel uncomfortable asking for this information or additional help. Lisa (Abbey House; anxiety) provides an interesting example. She is very familiar with Abbey House; her partner is one of its curators, and yet she still finds the layout of the museum confusing. Additionally, she expresses gratitude at how enthusiastic and helpful the staff members are, but she still feels anxiety over her presence at the museum: "I get self-conscious just because I know them and they're probably thinking 'what is she doing?'" (Appendix C 9.3) As mentioned in the vignette that began this section, an anxious brain, particularly one that is sensitive to social anxiety, will assume the worst possible outcome of a scenario, and often means that the person with anxiety will avoid social interactions, thus making person-based

forms of information inaccessible to them. It is not only general anxiety that can cause this heightened concern, but a wide variety of neurodivergent conditions, such as Autism, and chronic illnesses, such as diabetes, also can trigger anxiety disorders within a person.

Additionally, Lisa and Amy's experiences are contingent on staff members being present to answer these questions. As mentioned, Barley Hall has only one staff member positioned in the admissions area, which serves as both the entrance and exit (in pre-pandemic times). As such, if a visitor becomes lost or turned around, it is up to them to find their way out. Granted, Barley Hall is considerably smaller than either Abbey House or Treasurer's House, and in the original design of the museum, visitors will naturally retrace their steps in order to return to the admissions area. But still, there is a sense that the visitor is "on their own" once they leave the admissions area – both a blessing and a curse, it would seem, depending on what a visitor wants.

It should also be noted that this confusion regarding the layout presents itself across all types of conditions and disabilities. Dyslexia (Vidyasagar and Pammer 2010) is known to affect a person's spatial awareness, while ADHD (NHS 2021b) makes it difficult for someone to listen to a list of directions. Many mental illnesses, including anxiety (Cassidy et al. 2009; Chen et al. 2008; Sinoff and Werner 2003) and depression (McFarland and Vasterling 2018; Sapolsky 2001), can cause varying levels of memory loss, but especially short-term memory loss. Additionally, many people (myself included) have an auditory processing disorder (NHS 2021c), which means that they cannot fully process directions or instructions that are only given verbally. Memory decline (Small 2002) is also a natural part of growing older. All of these conditions can lead to difficulty remembering a series of directions. Not only that, it is perhaps the sign of a good visit that visitors become lost in their experience and forget mundane details such as the directions they were given when they first entered the building. It is therefore unfair of our unnamed reception host mentioned at the start of this section to blame visitors for getting turned around.

## 8.2. Lighting.

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"Oh wow, that's... quite a difference," Alfie says as we walk into the Great Chamber in Barley Hall. Alfie, who has dyslexia and monocular vision, is particularly sensitive to lighting levels in rooms. It has a massive impact on how well he can read, given that he has limited vision to begin with as well as a learning difficulty. Throughout our visit, we've been discussing the various text panels and how well he can read them. It's almost become a game for us by now, having me guess if a panel is easy or difficult for him to read as well as discussing what minor differences might be causing the discrepancy.

However, in this particular case, I have no doubt which panel is easier for Alfie to read and why.



*Figure 23. Two wall-mounted text panels hang side by side at Barley Hall, but with vastly different lighting levels on them.*

Two large text panels hang side by side in the Great Chamber, with similar layouts but identical materials, font styles and size, and where decorations were placed. Despite the similarities, the lighting levels are vastly different, and therefore Alfie's ability to read them is vastly different as well. His dyslexia and low vision make it difficult to read even the well-lit panel. As he put it, "I can stand here reading it, but I'll enjoy things and the place less."

The room in general is rather dark, lending a spooky atmosphere to an exhibit that has been set up to look like a medieval alchemist's lab. Amongst the objects themselves, there aren't many smaller text panels aside from small signs pleading to "not interfere with the experiments" – essentially, a themed "do not touch" sign that is remarkably rare at Barley Hall. However, two walls are lined with large text panels explaining the wider context of magic and science in the medieval era. If a visitor wants any amount of explanation about the strange apparatuses that are piled on the table, they must read these larger text panels.

And that is precisely the problem that Alfie has – due to the low light in the room, he can't read the panels easily, and doesn't want to bother even trying[7].

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Participants and staff members alike consistently comment on lighting conditions at all three sites. However, opinions are starkly divided: for some people, they enjoy the lowered lights, as they add to the overall atmosphere and experience. At Treasurer's House, for example, many people, both visitors and staff members alike, comment that they enjoy the lowered lights of the Blue Drawing Room as part of the temporary Christmas decorations. Parts of the room display are seen below in Figure 24 and Figure 25, showing the low lighting level. This is an intentional decision on the part of

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[7] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

the curatorial staff, as they are "setting a scene" to mimic walking into a room immediately after the end of a party. Small touches, such as empty champagne glasses and bottles (see Figure 24) on the floor, add to this atmosphere, and it is a very popular decision amongst my participants who have experienced it.
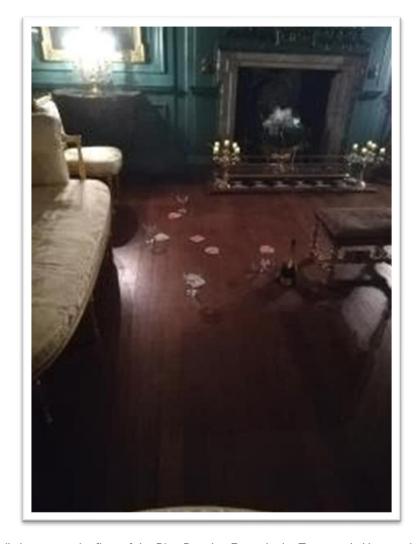


*Figure 24. A small vignette on the floor of the Blue Drawing Room in the Treasurer's House, showing the remains of a party.*

*Figure 25. A Christmas tree set up in the Blue Drawing Room in the Treasurer's House. The lighting in the room has been lowered to emphasise the fairy lights on the tree.*

In this case, the lowered lighting adds to the overall ambiance of the room, allowing people to slip into the scene that the curators have created and therefore more easily experience this historical, if fictional, moment. As Jessica (Treasurer's House; dyslexia, Irlen syndrome) points out, "people do go to these kinds of places because they want to kind of step through history and stuff like that" (Appendix C 7.3).

Additionally, some participants feel more comfortable in these low light areas. Amy (Treasurer's House; anxiety, hypermobility, OCD) and Lisa (Abbey House; anxiety) both comment that they generally prefer darker environments, as they "find it more calm and neutral" (Amy – Appendix C 4.3) and it makes them feel less "wobbly" (Lisa

– Appendix C 9.3). They specifically cite harsh, bright lighting as being disorientating and distracting to them, so these dimmer areas provide relief from the artificial lights of other, brighter areas.

However, many people find the lighting a hindrance to their experience. As Alfie (Barley Hall; dyslexia, monocular vision) simply describes, "it's very hard to read anything" (Appendix C 2.2). However, the lights are a hindrance to more than reading: some details of items on display are lost in the dim lights. When visiting the Queen's Room at Treasurer's House, a room guide pulls out a small torch to show James (Treasurer's House; fibromyalgia) and me the intricacy of the inlaid cabinets in the room, shown in Figure 26. There is an interesting dichotomy here: on one hand, Treasurer's House does not want to raise light levels in order to conserve the collection, yet they provide small LED torches in each room to better illuminate the collection. Providing torches shows that they know the light is too low for some details to be seen, yet they insist they cannot raise the lights due to conservation concerns.
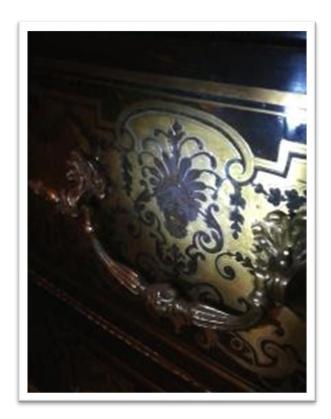


*Figure 26. Close up of inlaid cabinet at the Treasurer's House, with a room guide shining a torch on the detail.*

It is clear that the lighting has a significant, negative impact on the experience of most participants. This negative impact is particularly true for participants with disabilities that affect their reading ability, such as dyslexia or low-level vision. As Teagan (Abbey House; dyslexia, EDS), Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS), and I discuss in a later interview, a dyslexic brain already has to work harder to read text than a neurotypical brain, but the addition of low lighting makes the task even more difficult and laborious (Appendix C 8.4). This hindrance seemed particularly related to reading, as Alfie (Barley Hall; dyslexia, monocular vision) pointed out: "I can see what things are, I can't tell where they are. It doesn't matter so much, the details" (Appendix C 2.2). So long as details were unimportant and reading was not required, the low lighting was fine to most participants. However, it is highly doubtful that most heritage practitioners would agree that details or text are an unimportant aspect of the general museum experience.

Beyond an inconvenience, the lighting actually presents a physical danger to some participants. For Amanda (Barley Hall; heart failure, psoriatic arthritis), who earlier in our visit admits that she is slightly unsteady on her feet, having low light levels means that she could far more easily trip on something. "There were some places where I couldn't quite see and also you know, I like to see into a room – I have difficulty stepping into a room, so I do quite like to see what I'm stepping into" (Appendix C 3.3), she says. Additionally, Barley Hall has uneven floor surfaces in some parts, as the museum is a re-creation of a medieval townhouse and therefore includes re-creations of the flooring. There are also tall thresholds in the doorways of several of the rooms, shown in Figure 27, creating further trip hazards. The thresholds are historically accurate, as they stretch along the length of the building and hold the building itself together, making them structurally essential. These thresholds make an interesting point for interpretation, but they also make the building inaccessible to many people with mobility difficulties. When the uneven surfaces and thresholds are combined with extremely low light levels, certain visitors, like Amanda, merely peer into a room rather than entering it and risking a fall.
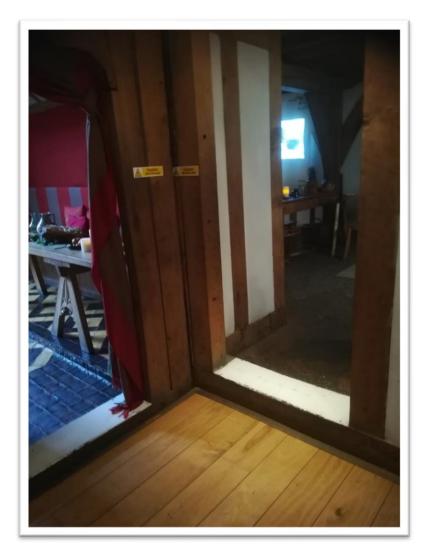
*Figure 27. Tall thresholds in the doorways between rooms at Barley Hall prevent level access and also create a trip hazard.*

It is not merely immediate physical dangers that are concerns for visitors; in some cases, low lighting lead to longer lasting side effects. Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) explains that certain types of lighting as well as the varying light levels could trigger one of her chronic vestibular migraines. She comments (Appendix C 4.1):

> Because it's a migraine trigger, it's something that I might not necessarily realise at the time, because it's kind of like an ambient issue. If it was getting to a point where I was like, I can't sit up anymore, I know that I could go and sit in the café or something, but the lighting is a bit harder to escape.

Our visit thankfully did not trigger a full migraine, but the potential for a migraine had been there, and it would have a significant impact on her activities outside of our museum visit.

Unfortunately, for one participant, physical side effects did accompany our visit. Jessica (Treasurer's House; dyslexia, Irlen syndrome) mentions a particular display in one of the rooms (Appendix C 7.3):

> The room when they had the ship in the middle of it [the Court Room], that was really dark. I just didn't really bother reading anything in there because it was just giving me too much of a headache.

Her headache comes from the combination of her disabilities: her dyslexia makes it difficult to read to begin with, so the low lighting strains her eyes and brain even more, while her Irlen syndrome causes her brain to interpret the light signals differently. With all these factors combine, Jessica leaves the museum tired, in pain, and feeling she has not had a meaningful experience, hardly the outcome museums hope to create (Appendix C 7.4).

Interestingly, many participants express a concern for the well-being of others in regards to the lighting as well. Lisa (Abbey House; anxiety) earlier mentions that she likes the lower lighting of the Victorian street, but she also admits "for anyone with any visual impairment, that would be quite dark" (Appendix C 9.3). Likewise, Jessica (Treasurer's House; dyslexia, Irlen syndrome) encourages museums to increase their lighting levels, saying (Appendix C 7.3):

> I imagine that people would rather be able to see than not see at all, so even the addition of just some lighting would be beneficial for me [and also] a lot of people... There's quite a lot of older people in there and I can't imagine that they have perfect 20/20 vision.

Both Lisa and Jessica acknowledge that the museum experience is not merely centred around them and their needs, but also the needs of other visitors to the museum. Lisa may find the lower lighting comforting, but she is aware that her preference is at odds with the accessibility needs of other visitors. On the other hand, Jessica prefers brighter lights, citing her disability, but also acknowledges that visitors with other disabilities would find brighter lighting levels beneficial as well.

Harkening back to Ellie, Jessica, and Amanda's comments above, there is a suspicious trend here that favours the wellbeing of the material assemblage over the wellbeing of the visitors. As previously described, Amanda and Ellie both are

concerned over the potential for injury during their visits, while Jessica in fact leaves the museum with a headache. However, when confronted with a request for brighter lights, organisations often cite conservation concerns as a reason to keep lights low or a desire to provide an "authentic" experience. Indeed, when room guides at Treasurer's House are asked about the lighting, they invariably provide one or both of these responses (Appendix D 4.2; 5.2; 7.2). If this is the case, the low lighting necessarily prioritises the collection and ambiance over the health and safety of the visitors, let alone their enjoyment. This prioritisation calls into question the entire point of these museums – do they exist to preserve a collection, or do they exist to engage the public with the past? National Trust claims to be "for everyone" (National Trust 2021c), but multiple participants leave Treasurer's House feeling unfulfilled (Appendix C 5.3; 7.3). YAT wants to "build better lives through heritage" (York Archaeological Trust 2021) but how can they when visitors to their attractions cannot engage with the heritage interpretation they present? LMG's aim to use their collection "as inspiration for education, entertaining, and inspiring the people of Leeds and beyond" (Leeds Museums and Galleries 2021b) rings hollow when they create environments that lead to visitors tripping and falling during their visit.

In addition to the conservation issue, the National Trust is also committed to lowering energy consumption at their sites (National Trust 2021d). The Trust is mindful that many of their properties, including Treasurer's House, are old buildings and therefore require large amounts of energy to operate, so they are committed to finding low-energy solutions. Ellen told me that the Treasurer's House was planning on introducing brighter, lower energy LED bulbs in two rooms during the Spring of 2020 (Appendix G 3.4). Once again, due to the pandemic, it is unclear on the status of these light bulbs. It is also unclear during my visit in July 2021 whether they have been installed, as the ambient light from the windows is much greater than it had been during my winter visits in 2019.

However, it is not only the level of light that is an issue but the positioning of these lights as well. Abbey House in particular has issues with such positioning, as Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) repeatedly points out during our visit. In one 'shop' on the Victorian Street, a bright spotlight is placed near the doorway. It allows people in the shop to see better, particularly when they are putting

on some of the provided dress-up clothes, but when she turns to leave the room, she is momentarily blinded by the spotlight thanks to its position. Additionally, there is a single step up to get to the door that she subsequently trips over, proving that the spotlight is not only a hindrance but a real danger. Although Kasi freely admits to being clumsy from time to time and her dyspraxia leads to difficulty with coordination, it is not her clumsiness that leads her to looking into the spotlight but rather the positioning of the light (Appendix D 1.2).

This spotlight is not the only light that is poorly positioned. Teagan (Abbey House; dyslexia, EDS) points out the lights in the Danger Zone temporary exhibition at Abbey House are situated in such a way that they create their own uneven shadows, shown below in Figure 28, (Appendix C 8.2). The harshness of the light also causes the sign itself to reflect some of the light, making it even more difficult to read. Much like with Alfie in the vignette above, the combination of lighting, materials, and placement make the sign so difficult for Kasi to read that she simply ignores it and moves on through the exhibition. It should also be noted that, although the Danger Zone exhibition is temporary, each temporary exhibition in this area utilizes the same basic format. In 2021, the temporary exhibition is "Sounds of Our City" and uses the same cases, same stands, and same style of interpretation panels, as shown in Figure 29 below. The consistency of the design means the lighting problem is present in both temporary exhibitions. Addressing this problem would then ensure the accessibility of future exhibitions as well, assuming they continue using the same layout.

*Figure 28. A text panel from the temporary exhibition Danger Zone at Abbey House.*
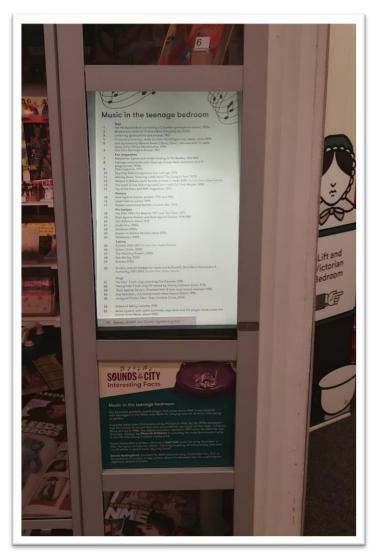
*Figure 29. A text panel from the temporary exhibition Sounds of Our City at Abbey House.*

## 8.3. Communal Reading.

I've known Jessica for a few years now. We've worked on multiple projects together, spent an entire year in classes together, and yet during that time, I had no idea she had a hidden disability. More interestingly, neither did she. About a year before my research, Jessica was diagnosed with dyslexia and Irlen syndrome. For further information on dyslexia and Irlen syndrome, see Chapter 6, but put simply, dyslexia is a neurodivergent learning disorder that generally makes it difficult to read while Irlen affects how the brain interprets light signals. These conditions, in turn, have an incredible impact on Jessica's

reading ability and therefore her engagement levels when she visits museums and heritage sites.

Since her diagnosis, Jessica has started using several tools that help her brain better interpret the signals it receives. In particular, she has a colour overlay, shown in Figure 30, which tints the text and background of whatever she places the overlay on. It's small, like an elongated A5 sheet, but that means it's subtle enough for her to feel comfortable using it. Comfort, as it turned out, was a huge aspect of whether or not she used her overlay, and therefore how easily she could read interpretation boards.



*Figure 30. Jessica using her coloured overlay on a personal interpretation board at Treasurer's House.*

Jessica and I visited Treasurer's House together, a site that has introduced what I have dubbed "personal interpretation boards." These boards are hand held,

movable, and have multiple copies so that several people can use them at the same time without crowding around one text panel. It is this personalisation that was crucial to Jessica's enjoyment. As we went around Treasurer's House, she picked up several of the personal interpretation boards and placed her overlay on them. As she describes it, "cI could put my overlay on it and not be embarrassed that people are trying to read it with me or anything like that. It was like my own little kind of panel for [the] five minutes I was having it. So that was quite nice actually. And it means that not everyone is kind of standing around one panel, people like to pick it up and then take it around the room with them."[8]

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Like Jessica, many of my participants dislike forced "communal reading" displays. In many traditional museums, a single large text panel is present, encouraging people to gather around and read from one communal board – hence, communal reading. Indeed, both Barley Hall and Abbey House utilise this method to varying levels. Most displays in Abbey House are of this single, large text panel template. Other displays have smaller text panels, but again, they are singular, stationary, and meant to be shared by multiple people at the same time.

Figure 31 shows one such panel from the temporary exhibition "Danger Zone" at Abbey House from 2019. These text panels have been created in line with the traditional wall panel – that is, each panel is anchored in one spot, immoveable, and thus forces multiple people to share the same panel – but it is much smaller than a traditional wall panel. The panel is about the size of an A3 sheet of paper, which makes it about twice the size of a regular piece of paper, but it is also mounted behind a pane of glass with walls on two sides, severely limiting the number of people who could view it at the same time. Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) also points out that, by putting it behind glass, she cannot touch the

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[8] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

board (Appendix C 8.2). The physicality of reading is particularly important to people with dyslexia, as their brains make text move around. Both Jessica (Treasurer's House; dyslexia, Irlen syndrome) and Alfie (Barley Hall; dyslexia, monocular vision) mention that either touching the text or having some kind of line guide, such as Jessica's overlay, is critical to keeping their place as they read through a paragraph (Appendix C 7.1; 2.1). In placing the text panel behind glass, Abbey House prevents Kasi from touching the board, causing her to struggle as she tries to read the board and not skip lines. In the end, she gives up and spends little time in the exhibition as a whole.



*Figure 31. Text panel from the Danger Zone at Abbey House, encased in glass at an angle with a bright spotlight on it.*

Lisa (Abbey House; anxiety) also mentions how she dislikes these communal reading panels. She comments that museums should have "more handout sheets to just pick up and read. If it's just on the wall or something, I tend to just scan it. Whereas with just a bit more time, I can hold it in my hand where I'm not sharing it with someone else. I would spend a little bit longer, not feel pushed to keep going" (Appendix C 9.3). This sentiment is echoed by Amy (Treasurer's House; anxiety, hypermobility, OCD): "I like that I can pick it up and take it around with me, so I don't feel like I'd have to stand in front of it or take it away from everybody else" (Appendix C 4.3). Their comments highlight an interesting aspect of a museum visit – the social pressure involved in the simple act of reading. If someone spends too long reading a stationary text panel, they prevent others from taking their place and thereby reading that same text panel. Dwell time in exhibitions has been widely studied (e.g., Chen et al. 2019; Na Ayudhya and Vavoula 2017; Schito and Testi 2017), but these studies focus more on how to increase dwell time or what causes people to shorten their dwell time. There is an inherent ableist assumption in all these studies, that if people linger at a particular piece of text, it is because they are interested in what the text is telling them. There is no mention of different reading speeds or the impact of learning difficulties or neurodiversity on dwell time. This only makes Amy and Lisa's point even more salient – by holding a personalised interpretation board, not only would their dwell time increase, but their overall enjoyment would increase as well, as well as lowering their anxiety that people are judging them for taking so long at a particular text panel.

At Barley Hall, the interpretation panels are more varied, with both large wall-mounted text panels alongside smaller, handheld panels that could be picked up by visitors. In the temporary exhibition Magic and Mystery, both sizes are designed into the exhibition. The wall-mounted panels discuss the larger narratives of magic, science, and how the two overlap in the Medieval mind, as well as highlighting specific themes and people such as medieval prophets or Albertus Magnus, like those shown in Figure 32. The smaller text panels are linked to specific items that they are placed near, such as a replica astrolabe or a bowl full of St John's Wort. These panels are either loose and can be handled by anyone, or are attached to stands that can still be picked up. Figure 33 shows a handheld panel about a witch bottle, an artefact that is on display in a case, with a copy of this panel in a holder on

the side of the case stand. As shown in the images, the design and theming for both the large panel and the small panel is consistent, tying them all together so that the size differences are not a distraction from the exhibit as a whole.



*Figure 32. Wall mounted text panel for the Magic and Mystery exhibit at Barley Hall.*

*Figure 33. Text panel for a witch bottle at Barley Hall.*

This mix of panel sizes is noted by several participants who visited Barley Hall. While the larger text panels are appreciated, it is the smaller panels that are particularly helpful. Alfie (Barley Hall; dyslexia, monocular vision) has difficulty reading the larger wall mounted text panels due to a variety of reasons (Appendix D 2.2). Between the low lighting, the quantity of text, and the stylistic choices of the board (font, spacing, and placing text over images), every single wall panel is difficult for him to read. But the smaller panels are a different story. By being able to pick up these smaller personal interpretation boards, Alfie is able to bring it closer to his face or take it to a brighter place in the room to read it more easily. The smaller panels still present some difficulty in reading them, but simply being able to move to better lighting

eliminates one of the barriers for Alfie and allowed him to read the signs with less difficulty.

Amanda (Barley Hall; heart failure, psoriatic arthritis) would have preferred different themes on the smaller panels, but appreciates them nonetheless. Her suggestion to Barley Hall is thus (Appendix C 3.3):

> "[Have those] information things as you're entering [a room]. There were one or two of those tablet type things, so if you hadn't purchased the book, it would be quite helpful. Somebody could pick [a panel] up as they went in the room.

Her arthritis makes it difficult for her to carry around a guide book, and information on the building itself is only available through that guide book. This in turn means that people like Amanda, who do not purchase the guidebook, miss out on information that they want, something that Amanda herself mentions a few times. But, as she also mentions, having small, hand held panels with information on the room and building itself would have greatly increased her enjoyment of Barley Hall.

At Treasurer's House, they have consciously made the decision to use only smaller boards – and multiple copies of each board as well. In each room, a stand holds three different sets of boards, each following a specific theme: Grand Designs, Frank Green, and Treasurer's Treasures. Figure 34 and Figure 35 show a sample stand and boards from one of the rooms. These themes are consistent throughout the house, so that visitors can follow as many of these themes as they like. As Jessica's vignette above shows, this decision to have multiple copies of smaller interpretation boards leads to a more meaningful, enjoyable experience. It is not only Jessica whose visit is enhanced: most participants in this research comment on how much they like or want these kinds of personal interpretation boards (Appendix C 2.3; 3.3; 4.3; 5.3; 6.3; 7.3; 9.3).

*Figure 34. The stand that holds personal interpretation boards at Treasurer's House – three copies of each thematic board, as well as a laminated packet of information regarding the objects in the room.*
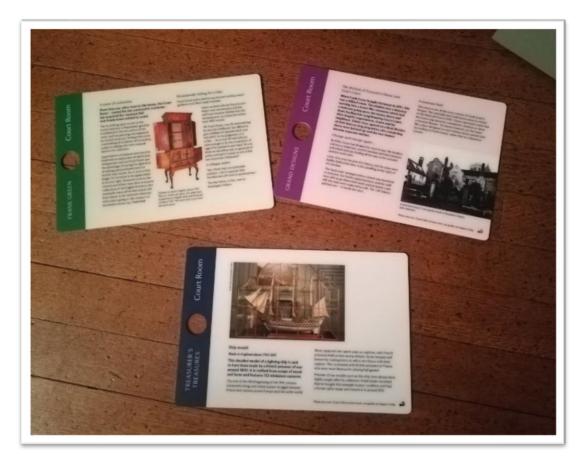
*Figure 35. Three personal interpretation boards, each highlighting the three different themes that are followed through Treasurer's House.*

Although it is unlikely these personal interpretation boards were originally created with accessibility in mind, they have proven to be a valuable accessibility asset. For Lisa and Amy, having this personal board to hold means that their anxiety does not make them feel pressured to move on before they had read everything. For Alfie, he can move the board to a different place in the room in order to read it, a crucial point given that he has quite severe visual difficulties. Amanda, although her disability is more physical, also makes an important point: given her arthritis, she may not be able to carry a guidebook around through the whole museum. But being able to pick up a smaller, lighter board that is relevant to only one room, then leave it behind when she is done with it, would give her the opportunity to learn the information she may have otherwise had to bypass in favour of physical comfort.

On the topic of physical comfort, Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) does mention that the panels at Treasurer's House were slightly unwieldy: "I think just size wise they were just that slightly awkward size that were slightly bigger than a A4 which I think it's just because you

know, you're used to holding something that's A4, it just felt a little bit awkward"
(Appendix C 5.3). This complaint is echoed by other participants to Treasurer's
House: Jessica (Treasurer's House; dyslexia, Irlen syndrome) mentions that "it was
quite hard to kind of navigate my overlay and the heavy panels at the same time"
(Appendix C 7.3) and James (Treasurer's House; fibromyalgia) also comments that
the boards were a bit on the heavy side (Appendix C 6.2). There is clearly room for
improvement, but as Ellie says, "in terms of the design and the intent behind [the
personal interpretation boards], I really like them" (Appendix C 5.3).

During the COVID-19, these personal interpretation boards and their cousins have
been some of the first things taken away from my case study sites. Treasurer's
House, once they finally re-opened, has removed them entirely. Partly this is due to
them being a touch point, something that museums are working to minimise, but it is
also partly due to the new tour-led experience at the House. There is no free-flow
aspect to a visit now, and all the content is dictated by the tour guide who led the
group around the building. Similarly, Abbey House has removed their smaller, hand-
held interpretation texts due to the pandemic.

Barley Hall is a slight anomaly compared to the other sites: it did not remove any of
the smaller, hand-held panels. Instead, they have added signs asking people to not
touch objects (but not the panels), placed hand sanitiser stations in every room, and
also introduced a cleaning crew that moves from site to site and cleans touch points
on a regular basis throughout the day. The cleaning crew are specifically instructed
to clean the hand-held panels as well, implying that they expected people to still hold
them.

## 8.4. Discussion.

Throughout this chapter, I have highlighted the barriers that my participants faced at
each case study site, as well as the passive accessibility measures that my
participants suggested. As a reminder, passive accessibility measures are
embedded into the design of an exhibition and require no gatekeeping, allowing all
visitors to freely use them. As a framework to highlight the efficacy of these passive
accessibility measures, I have adapted (McKercher and Darcy's (2018) hierarchy of

barriers, changing it into tiers of accessibility. I discussed their research in Chapter 3, and Figure 36 is their visualisation of these barriers:
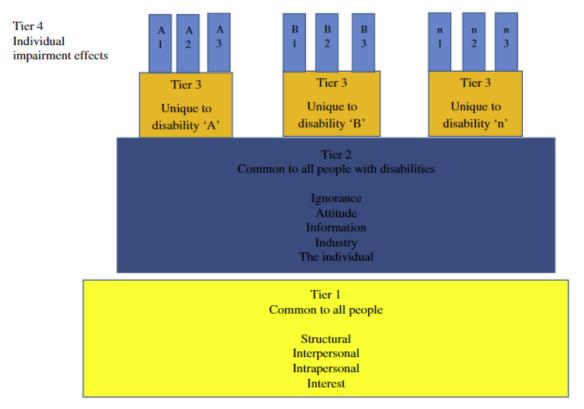


Fig. 1. Hierarchy of barriers to travel by people with disabilities.

*Figure 36. Hierarchy of Barriers figure, taken from McKercher and Darcy (2018, 60).*

In turn, I have created the following table to understand accessibility measures, shown in Figure 37.
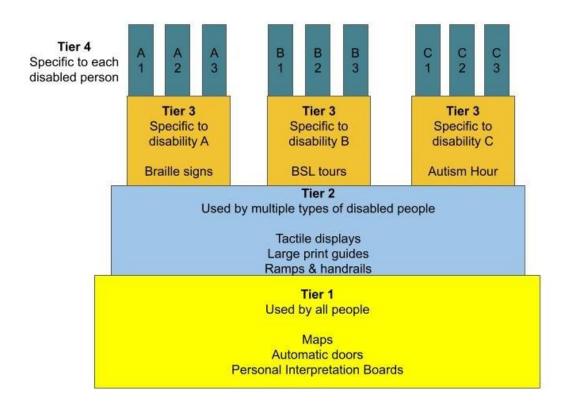
*Figure 37. Hierarchy of accessibility measures.*

Whereas McKercher and Darcy illustrate barriers to travel as experienced by disabled people, I illustrate how passive, embedded accessibility measures can benefit larger groups of people. Each tier represents how "universal" each accessibility measure can be, with the largest pool of potential users in Tier 1 and becoming progressively more specialised as the tiers rise. For example, all people can use automatic doors and find them particularly helpful, not only wheelchair users or people with arthritis, placing it in Tier 1. Likewise, people with many different disabilities and impairments benefit from using large print guides, meaning they are Tier 2. Measures such as Braille signage or BSL tours can only be utilised by people with specific disabilities, hence Tier 3. Tier 4 are tools specific to each person, such as Jessica's coloured overlay or Ellie's walking stick. Passive accessibility measures are embedded into the design process so as to be used by a wide range of people, placing them in Tier 2, if not Tier 1. Passive accessibility benefits far more people, tearing down disabling barriers and creating a more inclusive experience for all visitors.

In discussing each of the barriers I have presented in this chapter, participants did not merely point out how challenging these barriers are, but also often offer solutions or suggestions. Interestingly, many, if not all, of the suggestions put forward were passive accessibility measures, further emphasising the importance of passive accessibility. Participants do not want accessibility as an "add-on" measure, they want it embedded into the design of the experience. Perhaps their experience of having a hidden disability means they value these passive approaches all the more.

After the initial phase of data collection, I met with management staff at both Abbey House and Barley Hall to discuss my research findings and pass on participant suggestions. As mentioned in Chapter 6, I have been unable to reach anyone at Treasurer's House after the pandemic, and so was unable to present these findings to them. Below I discuss the proposed solutions to these challenging areas, as well as feedback from the sites' management where possible.

At first glance, it may seem that the layout of a building, especially a listed building, is something that cannot be altered. Whilst this is true, it would be a mistake to dismiss this problem as unsolvable. The very first thing Teagan (Abbey House; dyslexia, EDS) did when planning her visit was to see if they had a map of the site available (Appendix D 8.1). Other participants as well express a desire for some kind of map or guidance system at the sites. The physical layout of these sites cannot be changed, but providing maps to show the layout of the building is perceived as not only a suitable alternative, but is in fact a commonly desired item. Whether to help navigate a building, to ensure a visitor explores the entire site, or to target specific exhibits within the museum, participants want a map at the sites they visit. Indeed, there is already a recommendation from Kids in Museums (2018, 2) to provide maps to visitors.

In 2019, when I brought the confusing layout issue up to Ellen (Treasurer's House), she nodded understandingly. In order to alleviate this common complaint, Treasurer's House planned to release a new leaflet in spring of 2020, one that included a map of the site (Appendix G 3.4). However, as previously mentioned, the pandemic has changed a great number of plans, and no such leaflet has been produced. Further, post-pandemic, I was unable to ask anyone at Treasurer's House

about how their plans have changed and if these leaflets have been completely cancelled or merely postponed. Given that access to Treasurer's House is now through guided tours, it may seem there is less of a need for these maps. However, as my participants have explained, maps are a critical planning tool for people with hidden disabilities. Even if the free-flow experience never returns, I wonder if maps will be somehow incorporated into the experience.

Interestingly, due to the pandemic, Barley Hall seems to have fixed their layout challenge. As discussed in Chapter 7, they adapted their site to a one-way route, moving from a combined entrance/exit area to a separate entrance and exit. Visitors were also given hand-held maps to show them the way through the site, seen in Figure 38. In speaking with Maggie (Barley Hall), there was initial discussion of changing back to the single entrance/exit once pandemic restrictions were lifted. However, after listening to feedback from visitors, staff members, and my own research, they decided to keep the pandemic-induced layout, although they would be less stringent on the one-way system. Likewise, they would keep the hand-held maps, also due to this feedback (Appendix G 2.3).



*Figure 38. Handheld maps that are given to visitors at Barley Hall.*

At Abbey House, a one-way system was introduced in the Victorian Street due to COVID-19. The signage in the street was extremely helpful in orienting visitors through the street, allowing them to examine each of the small alleyways. In our meeting together, I spoke to Mary (Abbey House) about the usefulness of the "one way" signs in the street and she said that they had been working on developing a map for the site for some time now (Appendix G 1.3). After discussing this research, she suggests she has made the map a higher priority to be completed and introduced as soon as possible.

The lighting is a more difficult challenge to address, and thus far, no site has a solution that balances aesthetics, conservation, and readability. Although it is tempting to simply say "make the lighting brighter," the full picture is much more nuanced. As seen in section 8.2 above, not everyone likes having bright lights or indeed could even tolerate them. Some people also really enjoy the ambiance of a building that is closer to the historical lighting levels of the period it represents. Indeed, Barley Hall in particular is truly beautiful in the low light, and very much becomes a phenomenological experience in those moments, with the sights, sounds, and smells of a Medieval townhouse coming alive with the absence of obvious modern conveniences. Likewise, the staged moment in the Christmas decorations at Treasurer's House is hugely popular and, again, brings the experience alive in ways few other means of interpretation can. Treasurer's House feels lived in again, rather than a house frozen in time. Rather than visitors, people feel like they are invited guests trailing after a party. Abbey House too previously utilised a lighting cycle on their Victorian Street, simulating a day and night cycle. They had removed this particular aspect because visitors had complained that it was too difficult to read when the lights were low (Appendix G 1.1), but that in and of itself is precisely the reason for these nuanced approaches.

In areas where reading is an integral part of the experience, the lighting must be on the brighter side. According to Health and Safety Executive guidelines, the minimum level for reading is 100 lux (Health and Safety Executive 1997, 28). In a perfect world, text panels would be in well-lit areas, where visitors did not strain their eyes to read. Other areas could still have lower lights, creating a more atmospheric scene,

but those areas would not have text-based interpretation. Indeed, the presumption that interpretation must be text-based is a false one. Audio-visual presentations, videos, sound recordings, live interpreters, and even objects to manipulate are equally valid means of providing interpretation. Jessica (Treasurer's House; dyslexia, Irlen syndrome) even suggests that sites have a downloadable document on their website that visitors can load on their phone, allowing people to use their own devices (and personal accessibility tools, like a screen reader) even in darker rooms (Appendix C 7.3), while Alfie (Barley Hall; dyslexia, monocular vision) suggests an app with audio content (Appendix C 2.3). Both unintentionally support Moscardo's (2015, 296) assertion that "mobile apps offer tourists the ability to have greater control over their experience." While Moscardo likely did not write that with accessibility in mind, nevertheless these suggestions highlight the potential flexibility that digital tools offer.

Another way to counteract challenging light levels is through the personal interpretation boards described in section 8.3 above. These moveable boards mean that visitors who need more light can take them to another area that is brighter, potentially by a window or a lamp, without needing the whole room to be brighter. The aesthetic appeal of a room can be maintained whilst also allowing for reading lights.

Whilst only two sites have larger communal reading panels, each site has some version of a personal interpretation board. Invariably, the smaller, personal boards are popular amongst my participants for a variety of reasons. Some participants like how it allows them to spend more time with a particular piece of writing. Some participants like that they can move around with the boards. Some even like that it feels more personal and personalised, making their visit more memorable and meaningful. Whatever the reason, they are a passive accessibility measure that participants feel other sites should utilise more.

When I presented my research findings to Maggie (Barley Hall), she was very enthusiastic about trying to incorporate the personal interpretation boards into the exhibition. She told me that Barley Hall used to have similar panels in previous

exhibitions, but they had been removed during an exhibition change (Appendix G 2.3). At the time of this writing, she has already contacted the Head of Exhibitions and they are working on making personal interpretation boards for not just Barley Hall, but potentially also their other sites and the travelling exhibitions that The JORVIK Group lends out.

During my follow-up interview with Mary (Abbey House), she also expressed enthusiasm for the personal interpretation boards. She noted that they were planning on bringing back their smaller interpretation sheets once it was safe to do so and will be encouraging the curatorial staff to utilise these smaller style text panels in the future (Appendix G 1.3).

Unfortunately, I was unable to contact the management staff at Treasurer's House after the pandemic, but I wonder what their plans are going forward. There was great excitement in Winter of 2019 about the introduction of iPads to each room, mentioned in Chapter 6, so that room guides could show an archive of photos, articles, and other items that were not on display. However, with the new format, it seems like those iPads have been pulled, if they ever existed at all, along with the personal interpretation boards. Given the positive feedback on these boards, it is a disappointing omission and it will be interesting to see the impact of tour-only experiences going forward.

## 8.5. Summary.

My three case study sites have a mix of active and passive accessibility measures, a mix that has changed over the course of this research. Through site visits and interviews with my participants, as well as observations at these sites, it became clear that passive accessibility tools were the preferred method of my participants when it came to adapting a non-accessible area of their visit. The layout of a building could not be changed, but a map provided to all visitors was helpful not only as a navigation aid, but also as a planning tool. There may be no such thing as the "perfect" lighting level, but acknowledging the main use of a room, whether atmospheric or for reading, and lighting it accordingly was crucial for participants to actually engage with a room. Communal reading was disliked by a wide range of

participants for an equally wide range of reasons, and the introduction of personal interpretation boards offered them a much better alternative to larger, singular interpretation panels. These passive accessibility measures, built-in to the design of the site, were far more effective and used by far more people than active accessibility measures (e.g., touch tours kept behind the desk), proving once again that embedding accessibility into the design process is the most inclusive way of designing a heritage experience.

# Chapter 9 – Lack of Communication.

Some days, Barley Hall can feel empty. Only two front of house members and a duty manager are needed to run the site, and they rarely have any volunteers, aside from specific days when the "Barley Hall servants" are in residence.

On one of the days I'm there observing, it seems to be an unusually full day staff-wise. I'm standing at the admissions desk with Gwen, talking to her about the changes that have happened since the pandemic. As we're talking, the site manager Dean comes down from the office upstairs, pausing to chat with us at the desk. As a beekeeper in his spare time, he's working on a new interpretation panel to go with the "Buzz about York" initiative, a campaign to create bee-friendly areas and raise awareness about bees in the city. He needed to stretch his legs and step away from his computer, so he came downstairs to see how Gwen was doing and if I was getting enough data. The conversation only lasts a minute or two, and it never delves very deep, but there is a warmth to it that indicates a level of comfort between them.

A little while later, another manager comes down. This time it's Kieran, who is the duty manager for the day. He's doing the hourly walk-around, where the duty manager checks on staff members, walks through the site to make sure visitors are fine and nothing is out of order in the exhibits, and also checks the toilets to make sure they're clean and stocked. Today, Kieran is also carrying a bucket of sanitizing wipes to clean high traffic areas and touch points as well, such as handrails and signs. Again, he stops and chats with us for a few minutes, just small talk about how the day is going, if there are any visitors in at the moment, and how the rest of the day is looking. He might have stayed

and talked a little longer, but then a visitor enters the admissions area, so he leaves to let Gwen greet and admit them.

"Good afternoon," she smiles as the visitors step up to the admissions desk. "Do you have a booking with us?"

As she checks in the visitors, who have indeed pre-booked their tickets, she casually chats with them about how lovely the weather is, if a bit too hot when you're in the sun. She explains the changes that have taken place at Barley Hall because of COVID-19, and gestures to a basket of maps on the desk, saying they are free to take one if they'd like. The visitors do take one, asking how long they have to visit the museum. "Take as long as you like!" Gwen replies. "Most people spend about an hour, but we don't close for another few hours."

About half an hour later, I'm wrapping up my observations for the day. Barley Hall is closing soon, and while there's still a few visitors making their way through, the final time slot has already been admitted. The person who walks through the door, however, is not a visitor: it's one of the cleaning crew, Jared, making his rounds. The cleaning crew is tasked with visiting each of the sites and spot cleaning the high traffic touch points, filling up the hand sanitizer stations, and generally making sure that everything COVID-19-related is up to standards. As well as being part of the cleaning crew, Jared also works at the JORVIK Viking Centre as one of the costumed interpreters – he dresses up as a Viking and talks to visitors.

He also talks to his co-workers. Though he's only here to do some cleaning, he stops in and talks with both myself and Gwen. He hasn't been to Barley Hall very often, as he's only recently joined the cleaning crew, so this is actually the first time he's met Gwen. But the way they speak to each other, it's like they're old friends. There's a comradery that flows naturally, just as it did between Jess and the managers. In fact, every time I visit Barley Hall, both with participants

and to observe, there's an easy, familial feeling between the staff there, adding to the overall welcoming atmosphere of the place[9].

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The vignette above represents a small snapshot of Gwen's day, yet it encapsulates so much of the experience of a heritage site. Many types of interpersonal communication take place, often one flowing into another, and it is these interactions that I examine in this chapter. Specifically, I examine the meaningful communication inherent in these interactions and how communication is critical to creating inclusive, accessible experiences for both visitors and staff alike.

Of relevance here are the concepts of "dialogue" and "dialogic moments" - instances within interpersonal communication where dialogue is achieved. According to Black (2008, 98), "dialogic moments are fleeting, typically unplanned, instances where partners experience being both present and open to the other's experience." Kim and Kim (2008, 53) likewise position dialogue as the means through which people "freely interact with one another to understand mutually the self and others, resulting in the production and reproduction of rules, shared values, and public reasons for deliberation." Dialogue, then, is how people come to understand each other, and in the context of my research, how I come to understand the embodied knowledge of my participants.

Within this chapter, I examine not only the dialogic moments that I observed, but also where lack of dialogue, and lack of communication in general, hinders any potential for dialogue, particularly regarding accessibility. In the vignette above, Gwen interacts with multiple people. The moments may not be significant, such as her interaction with Jared, but they still allow for understanding between parties. Likewise, her interaction with Kieran represents another, more significant moment of communication. In each instance, the parties are "both present and open" (as per Black 2008, 98) in the conversation, creating dialogic moments that lay a foundation

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[9] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

for open communication. Although none of these instances were specifically in regards to accessibility, a foundation for open communication is critical in order to allow for such conversations to take place.

Below I examine communication in three distinct categories: visitor/staff interactions, team interactions, and hierarchical staff interactions. Visitor/staff interactions are the focus of much research (e.g., Pop and Borza 2015; Kim et al. 2012), and rightly so. This is where the visitor experience takes place, and the interaction between visitors and staff has a profound impact upon the visitor's enduring memory of a visit (Su and Teng 2018; Navarro et al. 2014; Mey and Mohamed 2010). Visitors can also provide critical feedback on accessibility (Lynch and Proverbs 2020; Gilmore and Rentschler 2002). However, front of house staff rarely are in positions of power to act upon the feedback they receive, instead relying on managers to further any suggestions front of house staff may give. Therefore, I also examine staff interactions to understand hindrances to implementing accessibility suggestions, dividing them between team and hierarchical staff interactions.

Team interactions refer to different staff groups cooperating with one another. In the vignette above, several staff teams communicate with one another. Gwen belongs to the Barley Hall front of house staff team, yet she interacts with the management team (Dean and Kieran) and the cleaning team (Jared). At Abbey House, there are similar teams: during my observations, I saw front of house, management, cleaning, and technical teams (Appendix G 1.1). At Treasurer's House, I observed admissions, café, volunteer, and management teams (Appendix G 3.1), although I understood the site also had conservation, cleaning, and gardening teams.

Likewise, I consider hierarchical staff interactions: in the vignette above, I classify the interaction between Gwen and Kieran as hierarchical. There is a power dynamic present in the conversation, as Kieran is undertaking one of his duties, performing his hourly check of the site. He is also attempting to elicit information from Gwen regarding the site – namely, if there are any visitors in at the moment or any problems she is aware of. The two are not interacting as members of different teams, but rather as a manager with their subordinate.

In examining the three types of interaction (visitor/staff, team, and hierarchical staff), I argue that communication, especially dialogue, is essential in creating an inclusive environment and dismantling barriers to accessibility. However, sometimes the barrier itself is a lack of communication. As in Chapter 8, I explore these interactions first using vignettes, exemplifying either communication or a lack thereof. Additionally, I use quotes from my participants as well as observations made during ethnographic study of my sites and interviews with staff to further understand how these types of interpersonal communications can impact the accessibility of a site. Due to my limited ethnographic observations (affected by COVID-19, see Chapter 6), I supplement my data with relevant academic research examining similar types of interactions. Finally, I discuss the implications of these interactions, arguing that dialogue between people is crucial in all three relationships (visitor/staff, team, hierarchical) in order to fully understand and accommodate the needs of visitors with hidden disabilities.

## 9.1. Visitor/Staff Interaction.

It's the end of November, and I'm walking through Treasurer's House with Ellie (anxiety, chronic vestibular migraines, depression, fibromyalgia). It's cold and damp outside, making it rather chilly inside this old Edwardian mansion. We're bundled up in coats and scarves, and knowing that these conditions can cause a flare-up of her fibromyalgia, Ellie has brought her walking cane. It's a collapsible cane, so she can carry it with her at all times, but she decided before we went into the House to unfold it and use it, just in case. There is a lot of walking and standing inside Treasurer's House.

But no one notices her cane (shown in Figure 39). True, it's a dark colour and blends in with her coat, but her coat doesn't reach the floor, while her cane does. She doesn't lean on it heavily as she stands, nor does she walk with a noticeable limp. Yet still, the cane is there. As we go around, I notice that my own legs are getting achy, mostly thanks to the weather, and every now and then, Ellie shifts on her feet a bit as she's standing. However, no one offers her

266

a chair or tells her where she can sit in each of the rooms. Seating can be a confusing matter in a National Trust property, as there's often several chairs that are "out of bounds" because they're part of the collection. In past years, they may have had a sign on them that said "do not touch" but National Trust is trying to move away from both signage and negative instructions. Still, that leaves us with rooms and rooms of chairs and nowhere to sit, nor anyone who offers us a seat.



*Figure 39. Ellie standing with her cane in Treasurer's House.*

Until we reach the basement, at least. It's a modern room, with patterned wooden floors and a screen with two sets of headphones attached. In the middle stands a large table with a 3D tactile model of the Roman fort that stood on the very spot now occupied by York Minster – and Treasurer's House. There are no room guides in here, but there is something far more important: **chairs**. The furniture is bare but abundant, with not only wooden chairs but also benches

and stools for people to sit on. Ellie immediately sinks down into a stool (shown in Figure 40), and lets out a small sigh of relief before she turns her attention to a video about the Romans in York. At last, she can rest her aching joints and give her full attention to Treasurer's House[10].



*Figure 40. Ellie sits on a wooden stool in Treasurer's House.*

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[10] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

In the vignette above, Ellie experiences a decided lack of communication from staff members regarding her disability and therefore her access needs. Indeed, only once we enter an unstaffed room, devoid of any opportunity to speak to staff members, is she able to finally address her accessibility needs herself. As I discuss in Chapter 7, the lack of chairs – or at least, the confusion over which chairs can be sat in and which are off-limits – at Treasurer's House is a source of great frustration to my participants. However, I would argue that the true barrier is not the lack of chairs, but rather the lack of communication between visitors and staff members regarding them. This lack of communication between visitors with hidden disabilities and staff members regarding accessibility is a common theme across all my case study sites.

To be clear, interactions between visitors and front of house staff members, as I observed both with my participants and in my ethnographic study, are overwhelmingly positive. No participants have any complaints about the staff members they interact with, and in fact, many comment on how accommodating and helpful staff were (Appendix C 1.3; 2.3; 3.3; 4.3; 5.3; 6.3; 7.3; 8.3; 9.3). On the surface, there is great satisfaction from my participants when it comes to visitor/staff interaction. However, the truth is more nuanced than this, especially when considering communication through the lens of dialogue.

As part of the post-visit interview, I ask participants if they thought they would have been treated differently if their disability was visible. Lisa (Abbey House; anxiety) immediately agrees (Appendix C 9.3):

> I think if you come in, if you have a physical disability, I think people are much more comfortable with offering you help, or asking if you need any help. They would, you know, 'just let me get that door for you.' … I think they would be much more open to asking you if you need help – which can be bad as well because it can presume that just because you're in a wheelchair, you need help and you're not independent. So I suppose it goes both ways. But they wouldn't look at me, especially because they know me, they wouldn't look at me and say 'do you need any help today?' And if they did, I'd probably say no, even if I was really anxious.

Lisa's observations are interesting because there is a tension between her wanting to have someone ask if she needs help, and yet not necessarily wanting to accept that help. This tension is a common theme for people with anxiety, such as Lisa

(Damer et al. 2010). Recall in Chapter 8, Amy (Treasurer's House; anxiety, hypermobility, OCD) says "I hate asking for things. I don't want to bother anyone" (Appendix C 4.2). Likewise, Lisa does not want to bother anyone, but there is a sense that the simple gesture of offering help would have been appreciated.

Lisa's comment is echoed in something else Amy shared in a later interview. When asked if she felt she had been treated differently from other visitors, Amy says (Appendix C 4.3):

> No, I don't think so. I'm just going to add that I almost would have liked to. Again, mainly referring to the fact that I went to sit down and that guy [the room guide] stayed on the other side of the room. Like I almost wish that they would have gone 'oh, do you want to sit?' But of course, they wouldn't have known to do that.

As a young, healthy-looking woman, there is no outward sign that Amy wants or needs any additional help. Yet, as she points out, when she does move to sit whilst talking to a room guide, it takes him several moments to follow her to keep the conversation going, and he also never confirms she could sit on the bench where she rests. At a site where it is difficult to know what can be touched and what cannot, a small comment of "yes, you can sit there" can make a significant difference.

James (Treasurer's House; fibromyalgia) feels the same. When asked if he felt he would have been treated differently had his disability been visible, he says (Appendix C 6.4):

> Probably, yes… You would feel, or you'd hope at least, that they'd be like, if you need to sit, take one, that type of thing… Because of the hidden disability, they think obviously, immediately there's nothing wrong with you until you say 'there's something wrong with me, and do you mind if I take this seat?' But I feel that if we did have a physical thing, walking around with a stick, they would say 'well do feel free to take a seat.'

Again, there is a sense that although they are treated comparably to nondisabled visitors, they want that extra measure of consideration that visibly disabled visitors might receive.

Aaron (Treasurer's House; autism, bipolar disorder, OCD) disagrees with this opinion, saying that if the room guides were aware of his disabilities, he expects

them to "[have a] look in their eyes, hair standing up on their arms, people kinda taking steps back" (Appendix C 1.3). Whether this expectation comes from personal experience was unclear, but it is yet another example of why people may not wish to disclose their disability (Menendez 2018; Cox 2013). Aaron's worry that people will treat him negatively based on his disability reflects the need for more open communication regarding accessibility – should he choose to disclose his accessibility needs, he should feel confident that people will discuss those needs with him and accommodate them as best as they can, not that they will immediately shut down the interaction and make him feel unwelcome.

The overwhelmingly positive opinion of my participants regarding the staff members indicates to me that any hesitation to ask for help came from an aspect of their disability rather than any staff member being unwelcoming. Indeed, when I ask Teagan (Abbey House; dyslexia, EDS) and Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS) about this contradiction between finding the staff friendly and approachable but not actually wanting to approach them, Teagan says (Appendix C 8.3):

> I think that's more Kasi's personality. She will literally start asking questions of whoever's standing there, just whoever is literally right next to her and her curiosity. [Her curiosity is] not as strong enough to actually go up and ask someone once she's left the particular area.

In this case, Kasi's ADHD means that she will turn to the nearest person to answer a question rather than spend additional time and attention in seeking out a staff member. It also echoes Lisa (Abbey House; anxiety) and Amy's (Treasurer's House; anxiety, hypermobility, OCD) comments about not wanting to bother anyone, a comment they make likely due to their anxiety.

However, as Amy, James (Treasurer's House; fibromyalgia), and Lisa have all pointed out, there is no outward sign for staff members to see that they needed help and therefore to initiate a conversation. Likewise, Amanda (Barley Hall; heart failure, psoriatic arthritis) notes that staff treated her the same as other visitors "probably because they didn't necessarily know I had a disability. I don't have a cane or anything" (Appendix C 3.3). On one hand, it is a good thing that they are treated the same as nondisabled visitors, especially given Aaron's comment. But as many have

mentioned, they would have liked to have been treated differently. There is still a sense from my participants that staff could have done more.

There is an interesting tension within all these comments – the desire to have their disability accommodated for, but without disclosing their disability. I discuss this quandary further below in section 9.4, but this is another example of the importance of Passive Accessibility, which I examine in Chapter 8. If, for example, all staff members mention where visitors can sit, then that particular accessibility need is accommodated for and no disabled visitors need to single themselves out. In fact, this is what happens at Barley Hall (Appendix D 2.2; G 2.1): the admissions person tells visitors that they are free to use the furniture as intended. In other words, they can sit anywhere they like. In this way, proper communication regarding accessibility is a passive accessibility measure, as it is built into the design of the exhibition through staff training.

Returning to my participants' belief that staff members could do more regarding the accessibility of their sites, the staff members and volunteers I interviewed agree. During my observations, I specifically ask them about the accessibility of the site. Almost everyone comments that there was only so much they could physically do with the site, as I discuss in Chapter 4, so they do what they can to compensate. At Barley Hall, Gwen speaks proudly about how, if a wheelchair user comes to Barley Hall, they offer free admission because a wheelchair user could only access the lower level, and even then, requires a portable ramp to be placed throughout the space to accommodate them (Appendix G 2.1). At Abbey House, Ella tells me about a time they had a visitor in an ECV[11]. The visitor could use the stairs, so using the lift was the only option to travel to the upper level. Unfortunately, the ECV turned out to be mere centimetres too large for the lift doors to close, even once they had removed the handles from inside the lift. As Ella recounts the incident to me, the disappointment in her voice is clear, despite doing everything possible to accommodate that visitor (Appendix G 1.1). Similar stories about helping (visibly) disabled visitors are shared over and over during my observations at all three sites, highlighting their commitment to accessibility and the experience of disabled visitors.

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[11] Electric conveyance vehicle - similar to a motorised wheelchair, but generally larger.

However, when I mention that I am particularly interested in visitors with hidden disabilities, many staff members express their own frustration over not knowing how to help. Carly, a volunteer at Treasurer's House, explains to me that although they are planning on introducing the sunflower lanyard scheme (discussed further below in section 4), staff at the property simply have no idea what else they could do (Appendix G 3.5). There is no doubt that for the staff members I interviewed, they str passionate about making their site as accessible as possible (Appendix G 1.2; 2.2; 3.2), but the lack of available research regarding accessibility for people with hidden disabilities proved a significant hindrance.

Both participants and staff alike express a desire to engage in open communication regarding accessibility, particularly for people with hidden disabilities. Participants like Amy (Treasurer's House; anxiety, hypermobility, OCD) and Lisa (Abbey House; anxiety) would like to be asked if they need help, even if they would not necessarily accept that help (Appendix C 4.3; 9.3). Staff members like Ella and Gwen acknowledge the limitations of their site and therefore want alternative means of increasing the accessibility of the site (Appendix G 1.1; 2.1), but they simply do not know where to start. It is the lack of dialogue (and information in general) that proves to be the true barrier here, something I explore further below in section 9.4.

## 9.2. Team Interactions.

I've spent a few days now at Treasurer's House, enough time that I recognize the admissions staff when I arrive and they recognize me. I'm still learning names, but they all know mine by now. They know that I'm here for my research, and they're very eager to tell me about accessibility-related things that I missed. On my second day there, both admissions staff members were very excited to tell me about the seeing eye service dog that visited less than an hour after I had left.

Soon enough, I settle into my usual position at the side of the desk, watching them interact with visitors and chat with each other. As time goes on, I notice

that I haven't seen anyone from "upstairs" come down – the management staff who run various teams within the property. When I ask about this, Lee, one of the admissions staff, tells me, "Oh, they're on call. If we have any problems, we can call whoever's on duty on the radio and they'll come and sort it out."

While I haven't seen any of the management staff, I have seen a lot of volunteers coming in and out of the little break room next to the admissions area. Like most National Trust properties, they have a large number of volunteers that operate as room guides, explaining to visitors about the history of the house and the special items within each room. It was often these volunteer room guides that my participants commented upon, saying how welcoming and friendly they were. There's an awful lot of them, up to 17 on any given day.

I comment to Lee that it must take a lot of memory work to remember all the volunteers. "They usually volunteer on a certain day each week," she explains. "So if they come in on a different day, I don't recognize them."[12]

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The concept of staff teams is not new, but I find the interaction – or rather, absence of interaction – between these teams fascinating during my ethnographic observations. In the vignette above, there is little to no interaction between the admissions team, the volunteer team, and the manager team. Even within teams at Treasurer's House, there is a further fracturing of groups: the volunteer team, easily the largest group within Treasurer's House, is divided from staff and further divided by which day a volunteer works at Treasurer's House, and is then even further divided into morning and afternoon shifts. Dr Heather Smith, Equity Officer for the National Trust and one of their officers on the national level (yet another team),

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[12] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

confirmed that this grouping of staff is usual practice for the Trust. The sheer number of teams within one property is almost overwhelming, and it is little wonder that Lee could not recognise each and every volunteer.

In truth, I see little interaction between the teams at Treasurer's House. During all of my time observing at the House, I only observe the managers descend the stairs once – when one of the National Trust official photographers visits Treasurer's House to take some publicity photos (Appendix G 3.1). Granted, as Lee explains in the vignette above, duty managers are only summoned downstairs when there is an emergency, so not seeing duty managers could simply mean that they are not needed on the days I visit. Likewise, I never spend time observing the café, so I cannot firmly state there is no interaction between them and other teams within Treasurer's House. However, given that the café is located in the basement – and on the opposite side of the basement from the stairs as well – it is highly doubtful that any of the teams would go out of their way to interact with the staff there.

The volunteers seem even more isolated, both from the paid staff and from each other. There is only ever one guide per room, and the only method of communication they have on them is a personal alarm that hangs around their neck that they can press in case of an emergency. They are reliant on the volunteer team leader to move from room to room and ensure that everything is running smoothly. To be fair to the volunteer team leaders, they do this regularly and to a timetable, so that the volunteers know when to expect their team leader and when they can take a break. However, given the scale of the property and how spread out the volunteers are, the lack of means to communicate between people and teams is slightly worrying.

The lack of interaction and communication between groups not only makes for a more isolating experience, but also makes it more difficult to identify and fix barriers to accessibility. During my visit with Amy (Treasurer's House; anxiety, hypermobility, OCD), she notes that the door to the toilets was very heavy and she worries about visitors not being able to move it (Appendix C 4.3). I subsequently mention the heavy door to front of house staff members, but they are completely unaware of the issue (Appendix G 3.1), presumably because they have a staff toilet to use and therefore do not use the public toilets. However, when I mention the heavy door to volunteers

at the property, they nod understandingly and comment that they agree it is too heavy, but also that they are unsure who to talk to about this particular issue (Appendix G 3.1). If there is more communication between teams, it is possible that not only would more people be aware of the heavy door, but that someone would know who to pass this feedback to and thereby fix the problem.

Communication between teams at Abbey House is more embedded within their everyday practice, perhaps because their staff teams are not as numerous. They have a front of house team, cleaning team, manager team, café team, and technical team. The front of house team can be divided further into an admissions team and a floor team, based on where the staff member is positioned. During my visits and observations, I never see admissions staff and floor staff switch places, although when I ask about the division of labour, staff member Danni explains to me that they all belong to the same pool of staff members, and everyone chooses which position they would like to stay at during the day (Appendix G 1.1). She also explains that people are welcome to swap positions throughout the day, but most people prefer either admissions or the museum floor (Appendix G 1.1).

When I visit with Teagan (Abbey House; dyslexia, EDS) and Kasi (Abbey House; ADHD, dyslexia, dyspraxia, EDS), we have a pushchair with us and therefore need to use the small platform lift to avoid the two steps between the admissions area and the Victorian Street. As we leave the admissions desk, the staff member there radios to another staff member that someone is coming through to use the platform lift. By the time we made it to the platform lift, this second staff member is standing there, waiting to welcome us and help us to use the platform lift. Both Teagan and Kasi comment on how smooth the interaction is, that it is a small gesture but one that is significant to their experience (Appendix D 8.2).

Although the interactions I see at Abbey House are limited, the wider atmosphere of the museum "family" is evident in many comments made by both staff and participants alike. Stephen, a staff member at Abbey House, tells me the staff "is like a big family, no matter [what position] you work. Everyone talks to everyone, shares their experiences with everyone" (Appendix G 1.1). Ella echoes this sentiment in her comment that Abbey House is her "home away from home" (Appendix G 1.1). Some

276

of this fondness can be attributed to the forced separation that came from the first national lockdown, but Lisa (Abbey House; anxiety) makes a similar comment during our interview in November 2019, well before the onset of the pandemic. Her partner works for Abbey House and Lisa comments that "this is one of the friendlier museums, I think probably because it's smaller" (Appendix C 9.3). Although both Treasurer's House and Barley Hall are described as "friendly" by the participants and staff members I interview, only Abbey House is described as a "family" or a "home away from home," implying a great amount of interaction between staff members.

Barley Hall is not described in quite so glowing terms, but it has a similar level of team interaction. Like Abbey House, Barley Hall has a front of house team, a cleaning team, a manager team, and a technical team, although unlike Abbey House, I do not see any members of the technical team during my visits with participants or my observations. Again, I have limited opportunity to observe interactions between staff, but even with these limited opportunities, I do see managers interacting with front of house staff on multiple occasions. Given the nature of these interactions, I discuss them further in section 8.3 below.

A unique aspect of Barley Hall, however, is that staff members do more than interact with other teams; some staff members move between teams. At least two members of the front of house staff are also part of the management team, serving as duty managers from time to time. Additionally, one front of house staff from Barley Hall is also a member of the cleaning crew. The permeability of these teams necessarily means that there is communication between them, as staff members interact with each other under a variety of circumstances and in a variety of roles.

Although I have limited opportunity to observe team interactions (or the absence of them) at my case study sites, my initial findings are in line with other research that has taken place. Robinson (2019), for example, found that a high degree of interdepartmental communication was key to successfully embedding human-rights related issues within museums. In order for significant, long-term relationships with external communities to be maintained, Robinson maintains that it cannot be only curators who are engaging with partner communities, it must also include "designers, programmers, and younger professional staff" (2019, 30). Applying this to my case

study sites, particularly as accessibility is a human rights issue, all teams, not only the management team, must be involved in uncovering barriers to accessibility through communicating with each other and with visitors. Gilmore and Rentschler (2002, 6) explicitly state this, saying "interdepartmental cooperation is a prerequisite for a museum to deliver excellent service in terms of education, accessibility, and communication." As I see very little interdepartmental cooperation at my case study sites, particularly at Treasurer's House, I am not surprised by the abundance of barriers to my participants.

## 9.3. Hierarchical Staff Interactions.

"I just don't understand why we can't do it!" Jamie hisses.

I'm standing at the admissions desk at Treasurer's House, and the Christmas season is in full swing. The House is decorated for the season, the special Christmas scones are available in the café, and families are arriving to meet with Father Christmas. In fact, it's this meet and greet with Father Christmas that is causing such a stir at the desk.

Understandably, there is a limited number of children allowed in each session with Father Christmas. This is in the days before COVID-19, so the limit is due to the size of the space where they meet him rather than a health concern regarding social distancing. Still, the limited numbers mean that tickets must be pre-booked for each time slot. That's not the problem.

The problem is that not all the slots are fully booked, yet the admissions desk can't sell more tickets to people who walk in asking for a ticket. On top of that, the booking system doesn't allow people to book tickets online for the same day, meaning these slots will remain unsold.

I've seen countless families now have to leave, trying to put on a brave face to hide the disappointment. It tugs at my heartstrings, and it's clearly having an

effect on the admissions staff too. They're still kind and understanding to the families they must turn away, but in between visitors, when there's a lull in the admissions area and no visitors are within earshot, the frustration comes out. "It's not like we'd be overbooking a session. And half the time, these people aren't even showing up for their session!"

While that may be a slight exaggeration, it is true that on multiple occasions, people who pre-booked a session with Father Christmas did not turn up – and for those same sessions, the admissions staff had to turn a family away. I ask why this is, and Jamie just shrugs. "We've asked and they say they can't do anything about it."[13]

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The vignette above demonstrates a lack of communication between front of house staff and management staff, what I call hierarchical interactions. The lack of reciprocal communication – that is, from front of house staff to management staff – not only engenders a sense of disempowerment amongst staff, but also prevents suggestions, particularly regarding accessibility, from ever being raised. In order to fully understand how important balanced hierarchical communication is, I here include a second vignette.

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Over at Barley Hall, a different system has arisen. Before the pandemic, there was no limit to the number of visitors allowed inside at a time, so pre-booking tickets was rare and often as part of a multi-site ticket. After the pandemic, however, numbers had to be monitored to allow social distancing, meaning all tickets had to be pre-booked.

This meant that only 8 visitors were allowed to enter the building every half an hour, and at first, there was no ability to sell tickets on the door, just like the Father Christmas sessions at Treasurer's House. As time went on, it became

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[13] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

clear that this was perhaps overly cautious, and, like the Father Christmas sessions, meant that people had to be turned away at the door. The procedures then changed: front of house staff were given the ability to sell tickets to walk-ins, with the understanding that there was space available for a particular time slot. If an admissions time slot was sold out, then they still had to turn people away or encourage them to book on to a different time slot, depending on the availability for the day. Likewise, if pre-booked visitors didn't show up for their allotted time, staff were allowed to admit walk-ins at their discretion. Indeed, as I conduct my observations at Barley Hall, the admissions staff member, Gwen, is able to admit three groups of walk-ins during the hour that I'm with her.

"It's nice," Gwen tells me as we discuss the adaptation of the procedure. "They trust us to get on with our job."[14]

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In comparing the two vignettes, the contrast is stark. At Treasurer's House, there had already been a dismissive attitude from the front of house staff that they could only receive information from management rather than also provide information back to them (Appendix G 3.2). At Barley Hall, however, communications appear to flow both ways, allowing a better experience for both the visitors who have not pre-booked and the staff who interact with them.

The differences at the sites go further than the flexibility of tickets. At Barley Hall, I ask about the relationship between the front of house staff and managers. Gwen enthusiastically responds that there is a good relationship there, that they "trust our responsibility and work ethic, we're not micromanaged" (Appendix G 2.1). She offers examples of front of house staff members taking on various projects, such as ensuring all the labels in the shop are standardised, of their own initiative and being supported by their managers.

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[14] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

Furthering this theme of trust, I witness several instances where the duty manager at Barley Hall begins their hourly walk around by stopping at the admissions desk and asking the front of house staff member for an update on the site (Appendix G 2.1). As Gwen points out, this is not perceived as an attempt at micromanaging or ensuring that the staff member is attending to their duties. Rather, it is understood as the manager trusting the front of house staff to tell them if there is anything that they should be aware of. For example, during one of their check-ins, George (front of house) explains to Kieran (management) that there is a couple in Barley Hall that are particularly interested in the architecture of the building, suggesting that Kieran could point out some of the original Medieval timbers to them if he encounters them. George's observation is not critical to the experience of the site for the visiting couple, but it does highlight the level of feedback that managers are open to at Barley Hall. Even a small suggestion that impacts only two visitors is taken seriously and, presumably, acted upon.

Gwen also says that managers are very open to suggestions regarding accessibility – provided there is capacity (Appendix G 2.1). She specifically refers to enabling subtitles on the introduction video that plays at the start of every time slot. A front of house staff member suggested that they should be turned on, acknowledging how it increased accessibility of the video, and the managers acted upon this suggestion. Information flows between staff hierarchies at Barley Hall, and this in turn increases the accessibility of the site.

Due to my limited observations at Abbey House, I am unable to observe hierarchical interactions between the management and front of house staff. Even when I visit with participants, front of house staff and managers have similar dress codes (at Barley Hall, the uniform for front of house staff and managers differs, allowing for easy identification) and I am therefore unable to discern between the two roles. It is possible that I witnessed interactions, but I was unable to understand how they might speak to internal staff hierarchies. However, the similar dress codes do present an interesting insight into how hierarchy is perceived at Abbey House: there is little formality to the hierarchical staff structure in general. Mary may be a senior management staff member at Abbey House Museum, and therefore has more power and influence, but she does not hold herself apart from the front of house team.

Indeed, this view of a more egalitarian staff structure is in keeping with my ethnographic observations at the site. I mention in section 9.2 above that front of house staff members feel like their co-workers are more like family, and this feeling extends beyond their immediate peers. Again, I do not witness any overt hierarchical interactions during my ethnographic observations, but my interviews with front of house staff and management are illuminating in this regard.

With Gwen's example of the Barley Hall subtitles in mind, I include a question about implementation of front of house suggestions in my interviews at Abbey House. Tim very proudly tells me about their suggestion for a "relaxed" Father Christmas encounter, something that has been enthusiastically accepted and implemented by the management (Appendix G 2.1). In the more typical Father Christmas sessions at Abbey House, children are lined up and brought into the grotto one by one to interact with Father Christmas and receive their gift from him. During the relaxed sessions, children are all brought into the grotto area together and are allowed to explore the area at their own pace and to approach Father Christmas in their own time, if they approach him at all. By avoiding enforced social interactions, autistic children and children with other social difficulties are more at ease in an otherwise alien and potentially scary environment. Again, this suggestion comes from the front of house staff, who see first-hand the discomfort of children with social difficulties, rather than the management. The dialogue between staff members and management has resulted in increasing the accessibility of the site.

I similarly ask Mary (Abbey House) if any accessibility suggestions from front of house staff have been implemented. She mentions the relaxed Father Christmas sessions, but focuses on another aspect: hand driers. During these relaxed sessions, which are primarily aimed at children with sensory difficulties, they turn off the hand driers in the toilets which are very loud and quite overwhelming for anyone with sensory difficulties (Appendix G 1.4). This too is a suggestion from front of house staff, who observed distressed children leaving the toilets because of the hand driers. Mary also tells me that for all events aimed at visitors with accessibility needs, not only relaxed Father Christmas sessions, they turn the hand driers off (Appendix G 1.4). Once again, the hierarchical communication between teams has ostensibly increased accessibility at Abbey House.

At Treasurer's House, there is a marked difference in the hierarchical interactions. In place of witnessing the interactions myself, I ask staff members how comfortable they were with their managers. All staff members say they have a positive relationship, and they feel they could go to their managers with any problem they encounter (Appendix G 3.1). However, as seen in the vignette, the positive relationship is not the full story.

During the course of my observations, I comment how dark the admissions area becomes during the afternoon, something I discuss in Chapter 8. As it turns out, staff members had asked for a desk lamp so that they could see better as they worked in a room with little natural light (Appendix G 3.1). However, it took several months for the management staff to supply them with a lamp, despite front of house staff members continually asking for any updates on the progress of their lamp, a sore point amongst the staff I speak to about this incident.

In a later interview with Issy, a front of house staff member, she explains a particular cycle she has witnessed at Treasurer's House repeatedly over the years that may help to explain the frustration (Appendix G 3.4). She says that whenever new elements are introduced to Treasurer's House, there is great excitement at first, with lots of discussion within a team about how this could be used to enhance a visitor's experience. Then comes a settling in phase, where people explore how to use the new element and incorporate it into their usual workflow. With this settling-in phase, new problems and issues arise, issues that the people who actually use the new element could not fix. This in turn leads to frustration and annoyance, and by the end of the winter season, most people have stopped using the new element. The most apparent problem in this cycle is the lack of a feedback mechanism, something that is obvious across many aspects of Treasurer's House. In Issy's cycle, there is no way for front of house staff to feedback the issues and problems that have arisen through the practical use of the new element. Likewise, across the wider experience of Treasurer's House, there is little opportunity for front of house staff to provide feedback to their managers.

I ask Ellen (Treasurer's House) about any feedback mechanisms they employ. She says that staff are always welcome to speak to the duty manager, and she hopes that they felt comfortable enough to do so. As mentioned earlier in this section, front of house staff members confirm they felt comfortable taking problems to the managers, but few of them actually do so. This mirrors what my participants say about staff members in section 9.1 above – they feel comfortable approaching staff, but they do not necessarily do so. Ellen also explain that at the end of each season, staff and volunteers are given a survey to fill out anonymously, reflecting upon their experiences throughout the year. The responses from this survey feed into training and changes for the next year. However, it should be noted that front of house staff operate on temporary contracts that last for one season, and therefore must re-apply for another temporary contract the following year. This turnover rate is another barrier to communication, particularly regarding accessibility, as staff are unable to continue pushing for any suggestions they have put forward.

Ironically, the volunteers at Treasurer's House occupy a more permanent position, as they are not bound to contracts. However, they are likewise dubious that their accessibility suggestions would be put into action. As part of my interviews at Treasurer's House, I ask each volunteer one thing they would change regarding the accessibility of the property. The results are always enlightening, and I soon begin asking staff members the same question. One volunteer, Caitlin, wants the building to be warmer and lighter (Appendix G 3.1), echoing what my participants said in Chapter 8. She even emphasises that there must be some balance between conservation and visitor (and staff) comfort (Appendix G 3.1). Another volunteer, Michael, wants the old toilets in the foyer, which are currently not used, to be turned into accessible toilets (Appendix G 3.1). As he points out, the only accessible toilet in the building is down a flight of stairs, across a narrow room, and then up another step. Additionally, as I mention above in section 9.2, the door to the toilets is incredibly heavy and difficult to open. Other suggestions include changing the taps in the toilets to a lever style, which makes them easier to turn, and reviewing their printed material to ensure it was accessible for people with colour vision deficiency[15].

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[15] Formerly referred to as "colour-blindness," colour vision deficiency is now that preferred term in the UK (NHS 2021).

At the time, I was unaware of the annual survey, but three volunteers, each of whom had been volunteering at the site for at least three years, expressed little hope that things would change, signalling a lack of faith in the survey results leading to anything (Appendix G 3.1). Although I was not able to view any of these surveys, the sense I received from volunteers is that even if they make suggestions in this survey, it is highly unlikely that the management would pursue any of these suggestions.

As Gilmore and Rentschler (2002, 6) write in their paper examining the role of museum management, "the views of all staff need to be encouraged and be accessible to senior management, and senior management should be seen to take these views into account and respond to them." It is clear from my ethnographic observations and interviews that the management at Abbey House and Barley Hall are living up to the standards of Gilmore and Rentschler, whilst the management at Treasurer's House falls short. Through these hierarchical interactions, new accessibility measures have been introduced at Abbey House and Barley Hall, creating a more inclusive experience for disabled visitors. By contrast, Treasurer's House, which lacks any significant hierarchical communication, prevents such changes from taking place.

## 9.4. Discussion.

Thus far in this chapter, I have shown a variety of interactions at my case study sites. Within each type (visitor/staff member, team, and hierarchical staff), communication – or more specifically, the lack thereof – is crucial to the accessibility of the site for disabled visitors. Barley Hall seems to understand the importance of communication between visitors and staff members, as they include an interesting line on their website: "Barley Hall staff are trained to uphold our safety procedures, and will be happy to answer any questions or note any suggestions you have" (The JORVIK Group 2021b). They openly welcome feedback from visitors, but who should initiate this conversation, and how?

In examining visitor/staff interactions, there is a feeling from both sides that they want some kind of communication, but neither side feels empowered to start the conversation. Participants are hesitant to identify their accessibility needs, whilst staff

members do not know when to offer help, nor what kind of help they could offer. To an extent, this is another reason why passive accessibility is key in creating inclusive environments, as then no one needs to ask or offer, the accessibility measure is part of the overall design of the experience. However, passive accessibility is not always possible, and even then, many heritage organisations are unsure how to include these passive accessibility measures in their offer. I discuss how this hesitancy stems from gaps in disability awareness in Chapter 10, demonstrating a kind of paralysis for many organisations when enacting accessibility changes. For now, I will focus on the method (or lack thereof) of communication between groups in order to argue that communication in all interactions is needed to understand the needs of visitors with hidden disabilities.

For communication in visitor/staff interactions, most research emphasises the need for staff training around disability awareness (e.g., Schitko and Simpson 2012; Bizjak et al. 2011; Daruwalla and Darcy 2005). However, I do not believe it is a lack of disability training that leads to a lack of communication between visitors and staff. Indeed, staff at all three sites receive disability training, as described in Chapter 6, and I witness during my observations and site visits staff members interacting with visibly disabled people, as well as hearing stories from staff members about memorable interactions in the past. The effectiveness of the training is clear to me, as staff members are confident in these interactions, offering help or subtly responding to a disabled visitor as necessary. Rather than a lack of training, I believe the key lies in the lack of signal for accommodation, the lack of cues for conversation. Recall how Amy (Treasurer's House; anxiety, hypermobility, OCD) says, "I almost wish that they would have gone 'oh, do you want to sit?' But of course, they wouldn't have known to do that" (Appendix C 4.3).

In recent years, there has been initiatives to bring awareness to hidden disabilities, the most popular and recognisable being the sunflower lanyard scheme (Hidden Disabilities 2021b). People with hidden disabilities wear a green lanyard around their neck that has sunflowers over it, such as in Figure 41, sometimes with a tag attached that gives further instruction. Initially, these tags simply state that the wearer has an unspecified hidden disability and that they may need extra assistance. Now, wearers can personalise them with their specific hidden disability, such as

fibromyalgia or PTSD, and include symbols to represent what assistance they may need. These lanyards are now recognised at airports, shops, on public transportation, and, of course, in museums and heritage sites. During the COVID-19 pandemic, the sunflower lanyard became a shorthand signal for someone who was medically exempt from wearing a face mask, and thereby gained more popularity and recognition.
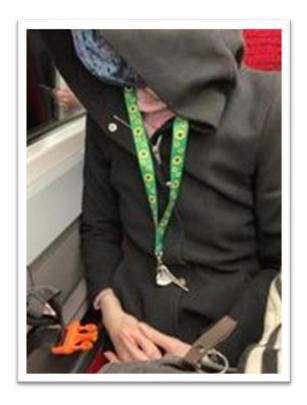


*Figure 41. Teagan wearing a sunflower lanyard on a train.*

At the time of my participant visits, the sunflower lanyard scheme was not as widely recognised as it is today. Indeed, at that time, none of my participants wore a sunflower lanyard on our site visits, although I now understand that several participants (Teagan, Amy, and Ellie) do wear them. I contacted each of these participants, asking for their experience in wearing the lanyard and if there has been any change in how people interacted with them. Teagan (Abbey House; dyslexia, EDS) says that although she does not notice any changes in behaviour from people she interacts with, "I will say that the lanyard scheme is helpful when you need to ask for help with a hidden disability" (Appendix C 8.5) She gives the example of using a toilet that is often for paid guests only – she feels that people would be more likely to allow her access if she wears a sunflower lanyard and asks to use their toilet than if

287

she does not have one, despite the fact that her disability and therefore her need to use a toilet immediately, has not changed.

Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) has a different view of the sunflower lanyard scheme. She admits that she only wears the lanyard when she is visiting somewhere she believes she will require extra help, such as train stations. Her reasoning is thus (Appendix C 5.4):

> I honestly don't know if I would wear one now because of the confusion around their use by people who are exempt from masks. I have complete sympathy with people who can't wear masks but sort of wish that there was another kind of lanyard they could use as I think people are much more aware of it now as just a mask exemption rather than also an indication of invisible disability! I'm also concerned by their co-option by some anti-vaccine campaigners/COVID deniers who are abusing the mask exemptions. I really feel like the meaning of the lanyard has changed so much over the past two years that it's not actually that useful for people with invisible disabilities any more.

Amy provides a similar response, writing that sometimes she makes a point of wearing her lanyard with her mask to remind people of the original intended use of the lanyard. She adds (Appendix C 4.4):

> Unfortunately, I think this is a case of a good thing being taken over by politics and it results in the meaning being lost. Part of me feels like I should continue to wear it and encourage others to do so as a form of reclaiming, but as the general public doesn't seem to be willing to have the conversation about what they are actually for, it seems it wouldn't be very useful.

Ellie and Amy make a similar point: the widespread use of the lanyards during the pandemic as a shorthand for "medically exempt from mask-wearing" has potentially limited the impact of the lanyards. People, staff members included, may only recognise the lanyard in its mask-wearing context, and then forget that the person wearing a lanyard may require additional help.

Unfortunately, there is little research regarding the efficacy of the sunflower lanyard scheme in the tourism industry. There are mentions in dental practice (Carr et al. 2020) and nursing studies (Maru et al. 2021) suggesting the use of the sunflower

lanyard scheme as a signal that the wearer needs extra assistance. There is also a call for submissions regarding museum experiences with the sunflower lanyard scheme (Front of House in Museums 2020), but it remains to be seen how effective these lanyards are in communicating the needs of people with hidden disabilities. Additionally, as Ellie and Amy point out, the lanyard's original intent has been transformed over the course of the pandemic and now represents something different to many people.

These lanyards can only go so far in increasing communication between groups, however. When it comes to team interactions, the importance of these interactions lies in the ability for people to communicate with one another. Where there is no interaction, there is no ability to pass suggestions (or warnings) along to co-workers. I show how important the ability to interact is in section 9.2 above, where a staff member radios another staff member to let them know we are coming to use the platform lift. Even this small interaction means that the other staff member had time to position themself in the best place to help us, making Teagan feel welcomed and included in the museum experience – not to mention, able to even access that area.

The opportunity for communication is equally as important for hierarchical interactions. Consider the presence of managers at each site: for Abbey House and Barley Hall, the duty manager is required to walk around the site regularly to ensure not only the site but also the staff are fine. At Treasurer's House, the managers only appear when there are emergencies that require their assistance. The opportunity for interaction between the front of house and management teams is nearly non-existent at Treasurer's House, while at Abbey House and Barley Hall, interaction between the two teams is almost a requirement of the managerial position.

Although I did not speak with anyone at Treasurer's House about these observations, I did bring this lack of interaction to the attention of Dr Heather Smith, Equity Officer for National Trust. She explains that some duty managers are more involved in the day-to-day running of their property, and that Treasurer's House does not necessarily reflect the norm across National Trust. She also acknowledges that there should be more interaction between the teams, particularly between front of house staff and management. To that end, National Trust has recently begun the

process of re-examining the role of duty managers and potentially making the role more active and in line with a service model rather than being available solely for emergencies. I understand "service model" to mean the service industry, where a duty manager is primarily concerned with the everyday details of running a site. The service model then is what is employed by both Abbey House and Barley Hall – yes, duty managers also have projects and other tasks to accomplish throughout their day, but these tasks will always come second to ensuring their site ran smoothly and their staff are supported. When I speak to both Maggie (Barley Hall) and Mary (Abbey House), they both confirm this interpretation of the role of duty manager at their sites (Appendix G 1.3; 2.3).

In examining the hierarchical interactions at my case study sites, I am struck by the differences in feedback mechanisms. At Abbey House and Barley Hall, the hourly walkaround provides front of house staff with multiple chances each day to feedback problems, no matter how small, to their managers. In turn, the front of house staff do not feel as if they are interrupting their managers with these issues. They are performing their job. Additionally, they feel trusted and empowered, leading them to suggest larger changes, such as more inclusive Father Christmas sessions at Abbey House or, as discussed in Chapter 8, keeping a new layout instead of reverting to the old one at Barley Hall. The different hierarchical levels are in constant communication with one another, feeding information back and forth to enhance the visitor experience.

At Treasurer's House, however, there is little chance for any communication amongst any staff teams. There is the annual anonymous survey, and whilst this is a form of feedback and a way for information to flow up the chain rather than down, this is still a one-way direction of information. Staff and volunteers, assuming that they bring up any problems at all, cannot discuss these problems and potential solutions with their managers, nor can managers ask for clarification or more explanation of any problems raised by staff members. There is no meaningful discussion here, no opportunity for dialogue. Staff feel disempowered and distrusted, as shown in the vignette for section 9.3 above, and indeed, there is an air of resignation at Treasurer's House when the subject of positive change was brought up, particularly involving accessibility. Many staff and volunteers want change and have many ideas

to increase accessibility, but they do not expect anything to happen. As the anonymous volunteer, telling me about new iPads that would be introduced to each room as an accessibility aid, comments, "I'll believe it when I see it" (Appendix G 3.1).

As I had limited opportunity to observe these particular communication dynamics in person, it is useful to look at another case study by Lynch and Proverbs (2020). Focusing on Knole, a Grade 1 listed building run by the National Trust, the authors investigate "how historic listed buildings are adapting to afford access to [disabled people] and how this is being achieved in the context of highly complex and interdependent legislative, technical, financial and social considerations" (Lynch and Proverbs 2020, 2). Whilst the entire study is illuminating and particularly pertinent to my research, of immediate interest here is their observations regarding the interdependency of management and volunteers in enacting accessibility measures. Specifically, they identify the Knole Access Team (KAT) meetings as the primary method of suggesting accessibility changes (10-11). As Lynch and Proverbs write (10-11):

> The meetings give volunteers a formal opportunity to speak to staff members, in the form of 'an easy discussion'... volunteers are encouraged to research and present their ideas prior to consideration. This shows a strong relationship where the paid staff take on the responsibilities of their role through a formalised process, with the volunteers creating and actioning potential changes through a less formalised process.

Although the focus of their research is on the intersectionality of conservation and accessibility, their observations of the KAT meetings exemplify how different types of interpersonal communications can lead to improvements in accessibility. The KAT is made up of people from different teams, including front of house staff, volunteers, and management. Their premises team is indirectly involved as well, as the results of the meetings are passed on to them. The meeting itself provides team interaction – the different teams come together to discuss accessibility, allowing for problem-solving and brainstorming. There is an understood visitor/staff interaction that informs these meetings as well: "volunteers are encouraged to research and present their ideas" (Lynch and Proverbs 2020, 10), implying that the volunteers produce

these ideas either from their interaction with disabled visitors or from their own experience as a disabled person.

But most interestingly is the hierarchical dialogue inherent to the KAT meetings. The authors describe these meetings as "an easy discussion" (10), which I take to mean a conversation that allows for a multi-way flow of information, for questions and answers and brainstorming amongst KAT members. Volunteers can rely on their managers to take their suggestions seriously, just as managers can rely on the volunteers to put forward suggestions that would create meaningful change for disabled visitors. The authors describe the "strong relationship" between the teams (11), and I believe that is a result of the dialogue embedded into these meetings.

The strength of these interactions is not merely the trust and respect engendered by dialogue, but in the tangible changes that have taken place at Knole as a direct result of the KAT meetings. The authors link a variety of accessibility-related changes that have taken place at Knole to the KAT meetings, including a dedicated drop off zone for disabled visitors, leaving manual doors open during operating hours, and the installation of an induction hearing loop (9-10), a device that allows people with hearing aids to connect to a hidden microphone and hear a speaker better. I mention these three changes specifically as they represent small changes with little to no impact on the fabric of a listed building that also have a minimal cost. As I explained in Chapter 3, I do not believe that most accessibility measures need to be costly or intrusive. They need to be informed by the lived experiences of disabled people, and the case study of Knole that Lynch and Proverbs present shows the importance of the three types of interactions I have outlined in this chapter. The lived experience of the disabled visitor is understood through communication with staff members, normally the front of house staff members. These staff members then discuss their observations with other staff members, growing their knowledge together and offering suggestions to dismantle barriers. Finally, these observations are fed upwards to management, who have the power to enact these suggestions in line with other organisational considerations, such as budgetary constraints or conservation considerations.

## 9.5. Summary.

In reviewing these instances of communication, it is clear that the lack of communication in hierarchical interactions is one of the greatest barriers to accessibility at my case study sites. The front of house staff are able to not only receive feedback from disabled visitors but they are also perfectly positioned to make their own observations regarding the accessibility of the site and supply that feedback as well. By interacting with other teams, these same staff members are able to compare observations and problem-solve solutions to the barriers they see. Finally, lower level staff members can feed these observations and suggestions to managers, who have the power to implement these suggestions. However, if there is a lack of communication in any of these interactions, especially in hierarchical staff interactions, the potential for improved accessibility is greatly restricted. The lack of communication, however, is symptomatic of a larger problem that I observed at my case study sites: gaps in disability awareness. In the next chapter, I explore this concept and how it is related to not only lack of communication but also active/passive accessibility.

# Chapter 10 – Gaps in Disability Awareness.

Standing at the admissions desk at Barley Hall, I'm talking with Gwen about all the changes to the site since the start of the COVID-19 pandemic. The interactive elements have all but vanished, something that Gwen hopes will prove to be temporary. The layout of the site has changed, splitting the admissions area from the shop and introducing a small video to welcome people to the site and explain the context of what they're about to experience. She's a bit sad about that too, as it means she only interacts with visitors when they're entering or leaving, rather than both, as she did before the pandemic.

But then we come to the subject of the maps that they now hand out to visitors, showing the one-way flow of the museum. "I haven't seen a lot of people really use them, honestly. I think they're a bit of a waste of time. I already have enough information to tell them when they arrive."

This is my opening. I had been very excited when I arrived and saw that Barley Hall had introduced maps, as this was something that my participants asked for repeatedly, no matter what site they visited.

"It's interesting you say that," I reply. "During my research, that's actually something that's been really popular. It's pretty easy for us to find our way around Barley Hall, we know the place, but some found it really confusing, so a map would help them orient themselves. Another one of my participants talked about how they used the maps to kind of plan out their time here, figuring out what they wanted to see most in case they didn't have the energy to see the whole site."

"Oh," she says, looking thoughtful. "I hadn't thought of it that way."[16]

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In Chapter 3, I discuss Fleet's idea of "encoded inhospitality" – unintentionally inaccessible coding within social media (2019). Additionally, Capitaine (2016) discusses the disconnect between the expectations of hotel managers and disabled visitors in regards to accessibility needs. I encountered similar ideas at my case study sites, where staff members and even the larger organisation had unintentionally created barriers for disabled visitors. I have framed this carelessness as "gaps in disability awareness" by which I mean people and organisations are unaware of what they do not know, often leading to disabling barriers because they do not have the lived experience of being disabled. Because most people do not have colour vision deficiency, they may not realise that colour-coded information is inaccessible to people who do have colour vision deficiency. There is no malice in their decision to use colour-coding, and yet they have created a barrier for others. As Gwen says in the vignette above, most places "hadn't thought of it that way" when it came to accessibility measures (Appendix G 2.1). More accurately, they had not thought of it at all. There is no overt discrimination meant in their actions and attitudes, but still, their ignorance has led to a level of inaccessibility for disabled visitors. This unintentional ignorance seems to be the overarching theme of all the issues with accessibility that my participants faced, connecting active/passive accessibility and lack of communication as the true root cause of the inaccessible barriers.

In this chapter, I re-examine the themes of Active vs Passive Accessibility and Lack of Communication through the lens of this gap in disability awareness, along with offering reflexive comments about how my own gaps in awareness impacted my research. I then examine a particular example of these gaps that was commented upon by my participants repeatedly: the banister at Treasurer's House. Finally, I end with a discussion about the implications of these gaps as well as how to combat it in

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[16] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

order to create more inclusive, accessible sites. It should be noted that, unlike Active and Passive Accessibility and Communication, I did not present this theme to the managers my case study sites, as at the time of my interviews, I was still in the process of conceptualising its importance and ramifications.

## 10.1. Active vs Passive Accessibility.

In Chapter 8, I discuss three specific barriers my participants encountered (layout, lighting, and communal reading) and also put forth their suggestions for mitigating these barriers in the context of active and passive accessibility. I now examine these barriers through the lens of gaps in disability awareness, arguing that passive accessibility opens up the possibility for positive effects despite these gaps.

In examining the other barriers presented in Chapter 8, it is clear that gaps in disability awareness are at play within each of these areas. The layout of the buildings was not created to exclude disabled people visiting. In some instances, such as the thresholds at Barley Hall, they are remnants of a previous era that does not translate well to a more accessible-minded present. The thresholds are required to hold the house together structurally, a technique that is historically accurate to the medieval period the house is supposed to date to. However, in maintaining the historical accuracy (and even structural stability), they have created an inaccessible site for people with mobility difficulties. The same holds true for the layouts of Abbey House and Treasurer's House – when they were adapted as heritage sites, they maintained a high level of inaccessibility for people with mobility difficulties. Out of the three sites, only one has a lift to reach the upper floors and only one currently offers a map to guide visitors around the site.

The same gaps in disability awareness are present in lighting levels – although there are arguably no gaps involved here but rather a dearth of acceptable solutions. At all three sites, lighting is predicated on the needs of the site, whether in regards to the collection or the ambiance of the experience. Even after bringing these barriers to the attention of the sites, there is little to imply that lighting levels are a complaint that would be given due consideration. Ellen (Treasurer's House) acknowledges that poor lighting is an ongoing battle, but implies that conservation would always trump

accessibility needs (Appendix G 3.4). Maggie (Barley Hall) says that she would speak with the technical team about what could be done, but the issue of lighting is not met with the same enthusiasm that the suggestions of personal interpretation boards or retaining maps were (Appendix G 2.3). Mary (Abbey House) agrees that lighting has been an issue in the past on the Victorian Street, so they have done away with the lighting cycle (Appendix G 1.3). However, her comment does not address how dark some of the shop interiors on the Victorian Street are. Although it is never verbalised, there is an attitude amongst the managers that they are unsure how to find an acceptable solution, one that satisfies accessibility, conservation, and energy-efficiency needs equally.

Finally, communal reading, which has been the traditional means of heritage interpretation for decades, was never meant to be a barrier to visitors, and yet, it has proven to be one of the most significant barriers my participants encountered. Large, wall-mounted text panels are seen at most heritage sites and museums around the world. However, their ubiquity means that no one has questioned how useful they truly are, particularly in terms of accessibility. Studies have been conducted about the height of these panels (Bitgood 2016), the font choice and font size (Laddusaw and Brett 2019; Smedley 2019), and even their digitization (Moscardo 2015), all in an effort to make the panels as accessible as possible.

I myself never questioned that communal reading itself was a barrier to many of my participants. My own gaps in disability awareness prevented me from entertaining alternative methods of disseminating interpretation. I had initially anticipated participants, particularly neurodivergent participants, would prefer aural means of interpretation, but I never considered how stressful reading in front of other people could be for people with a variety of disabilities. Likewise, I did not expect the personal interpretation boards to prove so inclusive, especially as they were not designed as an accessibility measure.

In an interesting twist, the personal interpretation boards prove that gaps in disability awareness are not insurmountable, and sometimes, these gaps are resolved unintentionally. Treasurer's House has introduced these boards, shown in Figure 42, as an alternative means of interpretation to the room guides available in each room.

Treasurer's House is in an interesting predicament, as they were bequeathed the site with all its contents under the premise that nothing would change (National Trust 2021g). No furniture removed, no large interpretation panels added, the site needed to be preserved exactly how Frank Green left it when he gave it to the National Trust. As a means of keeping their promise to Frank but also introducing alternative narrative themes, they have created the personal interpretation boards so that visitors could learn more about Frank Green himself, specific items of interest within the room, or the architectural evolution and influences throughout the property.



*Figure 42. Ellie holding a personal interpretation board at Treasurer's House.*

However, the boards have proven to be an excellent accessibility tool. Multiple participants comment on how they enjoy them and how the boards mitigate barriers that my participants encounter. For Jessica (Treasurer's House; dyslexia, Irlen syndrome), she can use her overlay without embarrassment (Appendix C 7.2). For

Alfie (Barley Hall; dyslexia, monocular vision), he can pick up the boards and move them closer to his face or to an area of the room with better lighting (Appendix C 2.2). For Lisa (Abbey House; anxiety), she can pick up the panel and move to an area where she feels less anxious about reading in front of people (Appendix C 9.3). As far as I am aware, none of these instances had been anticipated in the design of the boards, but still, my participants benefit from their creation.

The personal interpretation boards and maps prove the efficacy of passive accessibility as a means of counteracting gaps in disability awareness, even gaps that organisations are unaware of. Passive accessibility measures are, by their nature, embedded within a design and therefore are used by everyone. As such, they mediate a host of barriers that the original designers of the passive accessibility measure could never have anticipated. An automatic door is helpful for wheelchair users and people with pushchairs, but it is also helpful for people with arthritis or people with their arms full of boxes. Maps are created to help people orient themselves within a site, but they can also be used by a visitor to prioritise the exhibitions they want to see or to estimate how much energy is needed to see the rest of a site. Personal interpretation boards can introduce alternative narratives within a site, but they also can be used by people too nervous to use an accessibility tool in front of other people or are too nervous around other people altogether.

## 10.2. Lack of Communication.

In Chapter 9, I discuss how the lack of communication between groups creates one of the biggest barriers to accessibility. I now examine this lack of communication through the lens gaps in disability awareness, arguing that increased communication leads to increased accessibility by exposing these gaps.

A common theme amongst both participants and staff members is the inability to know how or when to ask for help. Participants want staff members to ask if they needed any help (Appendix C 4.3; 6.4; 9.3), whilst staff members want some external signal that someone needed help (Appendix G 3.1). Both sides agree that staff seem perfectly willing to help if called upon, but participants face a great number of barriers in trying to communicate their needs without disclosing their

personal medical history and potentially opening themselves up to abuse (e.g., Menendez 2018; Cox 2013).

One such solution is the sunflower lanyard scheme, also discussed in Chapter 9. However, as Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) says, "I really feel like the meaning of the lanyard has changed so much over the past two years that it's not actually that useful for people with invisible disabilities any more" (Appendix C 5.4). There is no longer a guarantee that staff will acknowledge the sunflower lanyard as anything other than an exemption from wearing a facemask, which alters the original purpose of the lanyard. True, many people are exempt from wearing a facemask **because** of their hidden disability, but, according to my participants, somehow the ubiquity of the lanyard now means far fewer people are going out of their way to help people wearing the lanyard. In a way, the increase in awareness has led to an increase in ignorance as well.

As facemask wearing seems to be with us for the foreseeable future (Tuñón-Molina et al. 2021), I argue that better staff training needs to be implemented. As mentioned in Chapter 6, all case study sites provide their staff members with disability awareness training of some type. I was unable to obtain details of the disability training at Treasurer's House (and indeed, two staff members told me they received no such training), but at Abbey House and Barley Hall, this training includes awareness of hidden disabilities, particularly dementia and autism. However, as I discuss in Chapter 3, there are far more hidden disabilities than dementia and autism. It is encouraging that these sites have trained their staff in assisting visitors with dementia or autism, but more is needed. There are multiple courses that focus on hidden disability awareness, including one from the Sunflower Lanyard Scheme itself (Hidden Disabilities 2021b). I have not been able to examine these training materials myself, but as Bizjak et al. (2011) shows, even a small amount of exposure to disability issues is enough to increase positive attitudes towards disabled people. Likewise, Daruwalla and Darcy (2005) demonstrate that ongoing training, particularly in the form of refresher courses, maintains that positive attitude, and perhaps that is what the staff at my case study sites require: a refresher course. Acknowledging that the sunflower lanyard has changed in its cultural meaning, but reminding staff of the

original purpose of the lanyard could go a long way in empowering staff members to ask visitors if they need help.

The lack of communication between staff teams also allows gaps in disability awareness to fester. At Treasurer's House, teams remain isolated from each other, meaning that they cannot discuss observations or encounters. Recall the heavy door I mention in Chapter 9 – the admissions staff are unaware of the issue, but the volunteer team, who are aware of the issue, do not know how to fix it or who to speak to about it. Contrast that with the interaction between teams at Abbey House and Barley Hall. Not only do staff communicate within their teams, such as the staff member on the admissions desk at Abbey House alerting the staff member near the platform lift that someone is coming their way, but they also communicate with other teams, such as front of house staff at Barley Hall passing information to managers regarding visitors in the attraction. The flow of small, seemingly insignificant details between the teams creates an environment for communication and discussion that can not only identify problems but also work towards solutions. Perhaps if the volunteers and admissions staff at Treasurer's House have better methods of communication between their teams, they would have some suggestions for the heavy door problem.

Even more critical is the lack of communication between staff across institutional hierarchies. As has been mentioned multiple times, Capitaine's (2016) research exposes the gaps in disability awareness of hotel managers regarding the needs of disabled visitors. These gaps lead them to make a number of inaccurate assumptions regarding alterations to their hotel rooms when the reality is that many disabled visitors need small accommodations, such as a corner of a room key card cut so they know which way to insert the card into the door lock. Likewise, there is a significant disconnect between the expectations of the case study site managers and the actual needs of my participants. I discuss this disconnect in Chapter 9, but here I examine how this disconnect is informed by gaps in disability awareness and the lack of communication within hierarchies.

As discussed previously, there is a significant lack of communication at Treasurer's House. Not only do front of house staff teams not interact often with management

teams, there is a decided lack of trust in those interactions producing any change. The incident of the front desk lamp (Appendix G 3.1) is a perfect example, highlighting the effect of the management's gap in awareness: the front of house wants a desk lamp in a room that had little to no light-sensitive materials, meaning there is little concern for light damage in that room. Yet it still takes management months to fulfil the request, potentially because they do not experience the low light levels themselves and therefore did not understand the necessity of the lamp. The management offices are upstairs in a more modern section of Treasurer's House with a modern overhead lighting system. They are not beholden to natural light to work, whereas it is the primary light source in the admissions area. Their lack of awareness of the working conditions of their staff members leads to a delay in improving basic working conditions. Additionally, it creates an environment where the front of house staff members do not trust their managers to take their suggestions and requests seriously. Every time I mention the lamp to front of house staff members in our interviews, they scoff or make some kind of derisive comment about how long it took for management to supply the lamp (Appendix G 3.1). The volunteers likewise express doubt that promises would be kept, as one volunteer eloquently comments "I'll believe it when I see it" (Appendix G 3.1). With so little faith in the communication systems at Treasurer's House, many staff members have little incentive to question and identify gaps in disability awareness they observe throughout the property, as there is little hope for change.

## 10.3. The Banister.

At the Treasurer's House, everyone looks forward to the Christmas season. There is a palpable excitement in the air, knowing what is to come. For when the Christmas season descends, the Treasurer's House is decorated for the holiday.

Each room has its own special touch. The lobby, where the visitors first enter, has a display of over-sized tree baubles webbed together in the fireplace grate. The great hall has a large pile of brightly wrapped presents at the hearth. The Blue Drawing Room has a small vignette of empty champagne bottles and

glasses, giving the feeling of just missing a lively yet intimate party. Even the staircases are spruced up for the holidays, with garlands of greenery and red tartan ribbon wrapped around the handrail, shown in Figure 43.



*Figure 43. The banister at Treasurer's House wrapped in a Christmas garland.*

But for many, many visitors to the Treasurer's House, this aesthetic prevents them from being able to get around the House. The banister of the William and Mary staircase, the only staircase that connects the upper and lower floors of the northern wing, has a beautiful garland wrapped around it. However, the placement of the garland prevents most people from being able to use the banister to help themselves traverse the stairs.

As we approach the stairs, James almost does a double-take, looking at the garland wrapped around the banister. He looks at me, giving me a "can you believe this?" expression, and starts his way up the stairs. At the top, he all but collapses in the first chair that looks like it isn't off-limits. I'm struck by the fact that there's no outward sign of his pain – no grimaces, no limping, no sigh of relief when he's finally off his feet. Earlier, he had told me that he was experiencing a "medium pain" day, and I can imagine that travelling up the stairs without the benefit of a handrail has not helped at all.

Later on, as we are sipping hot chocolate and discussing our visit, I ask him if he noticed any barriers as we went around. "Oh yeah, the handrail was such a bad idea on accessibility issues. It was just wrong on every level."

A few minutes later, I ask him if there's anything the museum should design into the exhibition from the beginning. "More handrails, more sort of things that you can just pull – even on only two or three steps."

Finally, I ask him if there's anything he'd like to tell the museum regarding their accessibility. He grins at me. "Guess."

"Is it going to be handrails?"

"Yes!" he laughs. "Funny that."

We talk a few minutes longer, making plans for our follow-up meeting. He mentions the garland on the banister again, but this time, there's no humour in his voice. "It may not seem like anything to them, but it makes a big difference."[17]

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[17] As mentioned in Chapter 6, I sent each vignette to the appropriate participant in order to ensure I captured their thought process and feelings accurately. Each has been included in this thesis with their approval.

James is not alone in his despair over the garland on the banister. It is mentioned by every single participant that visited the Treasurer's House during the Christmas period. Amy (Treasurer's House; anxiety, hypermobility, OCD) puts it most eloquently: "[it was like it] hadn't even crossed their mind that that might be an issue" (Appendix C 4.3).

The banister serves as a perfect example of the impact of gaps in disability awareness. As the staff decorate Treasurer's House, they are more concerned with aesthetics than with practicality. This is understandable, as the aesthetic value of the decorations is their primary purpose. However, aesthetics and accessibility need not compete with each other. Simply hanging the garland along the side of the banister, shown in Figure 44, rather than on top of it, shown in Figure 45, would satisfy both conditions. It is a small detail, but one that has a significant impact on most of my participants' visits to Treasurer's House. James and Amy's comments have already been mentioned, but Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia) likewise comments that "even if you don't have any accessibility issues, it's just kind of natural. You go to grab a banister, but you just get a battery pack in your hand" (Appendix C 5.3). Aaron (Treasurer's House; autism, bipolar disorder, OCD) does precisely that during our site visit – he reaches for the banister but instead grabs the garland (Appendix D 1.2). He immediately withdraws his hand and continues up the stairs without any aid, despite being slightly unsteady on his feet. Likewise, during my observations, I notice multiple visitors perform the same action: they reach out to use the banister, only to immediately withdraw their hand when they either see or touch the garland that is in the way (Appendix G 3.1).

*Figure 44. The Great Hall staircase at Treasurer's House with a properly hung garland.*

*Figure 45. The William and Mary staircase at Treasurer's House with an inaccessibly hung garland.*

Interestingly, the original design of the decorations avoids this particular problem. According to Alice, who is in charge of overseeing the design and installation of the decorations, the garland is always meant to hang along the side of the banister so that it would not impede visitors' use of the banister (Appendix G 3.1). However, the original intention had not been communicated to the volunteers who hung the banister, and instead this unfortunately memorable situation was created.

As passive accessibility is an accessibility measure built into the design, the banister is a passive accessibility aid. All of my participants to Treasurer's House use (or attempted to use) the banister as they traverse the staircase (Appendix D 1.3; 4.3; 5.3; 6.3). Likewise, during my observations, it is rare that, once the garland has been

adjusted, a visitor does not use the banister (Appendix G 3.1). Although perhaps not intentionally built to help people with mobility difficulties use the stairs, it now can be viewed as one of many passive accessibility measures across not only Treasurer's House but in buildings across the world. However, the ignorant placement of the garland takes away the passivity of the banister. Indeed, the garland takes away its usefulness altogether. Neither active nor passive, it is no longer an accessibility measure at all.

Additionally, the miscommunication represents a lack of communication across the staff hierarchy at Treasurer's House and potentially a lack of within-team communication as well. As mentioned above, the original design has the garland hanging to the side of the banister, leaving the banister free for people to use. Alice specifically notes that it has been designed with accessibility in mind. However, that intention is never communicated to the people who installed the garland. Admittedly, I was not present whilst Treasurer's House was being decorated, but given the miscommunication, I can only assume that Alice – or at least someone who was familiar with the intent of the design – was not present as the garland was being placed. The instruction was given, and then the management team moved to a different area to take care of another task. In such an instance, the volunteer team was unable to ask questions regarding the placement, to seek clarification, or even to accept correction from someone familiar with the intended design.

Even once the garland has been placed, it takes nearly a month for it to be corrected. I am unsure of the exact date it is fixed, but my participants note the garland throughout November. When I begin my observations on 8th December, the garland is still hung inaccessibly. When I return on the 16th, it had been fixed. This may seem a trivial detail in the wider scheme of accessibility, but all five of my participants who encounter the garland-strewn banister take issue with it. Multiple visitors I observe also have difficulties with it. Yet it still takes at least three weeks for the problem to be corrected, during the busiest time of year for Treasurer's House, and I can only wonder: how many people are negatively affected by this mistake – an example of a gap in disability awareness on the part of Treasurer's House?

Interestingly, when I visit Treasurer's House in July 2021 to observe the COVID-19 changes, the banister once again catches my eye. Similar to the Christmas decorations that festooned the banister before the pandemic, there is now a long length of blue foam that covers it, as seen in Figure 46. When asked about this, my tour guide explains that it has to do with the new cleaning procedures. Too much sanitizing spray is destructive to the wood, so the banister is wrapped in foam to protect the wood and also allow for increased cleaning, which keeps visitors safe. The crucial difference, however, is that this blue foam does not prevent people from using the banister.

It does not escape my attention that conservation concerns are paramount to the installation of the blue foam, nor that aesthetic appeal is sacrificed in favour of preservation. Given how long it took for Treasurer's House to adjust the garland, I highly doubt accessibility would ever triumph in the same way that conservation has.



Figure 46. The William and Mary staircase banister at Treasurer's House wrapped in blue foam.

## 10.4. Filling the Gaps.

It would be reductive to say that the barriers to inclusion stemming from active/passive accessibility and lack of communication are ultimately caused by gaps in disability awareness on the part of my case study sites. The truth is far more nuanced, and indeed, I believe these themes all feed into each other. Passive accessibility measures, such as maps or personal interpretation boards, can expose gaps in disability awareness by mitigating a barrier that heritage organisations were unaware even existed. However, these gaps also mean that places are unaware of the passive accessibility measures that their site (and their visitors) could benefit from. Likewise, communication can expose gaps in disability awareness, but these gaps can also feed and encourage lack of communication. As shown in the banister example above, there is a complex network of all three elements that lead to inaccessibility, however unintentional.

At the heart of it, however, gaps in disability awareness comes from ignorance, and the only way to combat such ignorance is through knowledge sharing and the unlearning of problematic behaviours. Let us take the common refrain from multiple voices in my research: staff, and indeed, organisations, simply do not know where to start. All three case study sites expressed a desire to understand how to increase accessibility for visitors with hidden disabilities, but these same sites did not know how to obtain this knowledge. As discussed in Chapter 3, very little research has been conducted in the particular area of accessibility for people with hidden disabilities, and no research has incorporated a great level of detail in understanding these accessibility needs. But likewise, my participants were unaware of the structural barriers that prevented their suggestions from being put into action. Indeed, at the beginning of my research, I was unaware of these structural barriers as well.

But these gaps were also precisely the reason I focused on the lived experience of people with hidden disabilities. They are the experts with embodied knowledge of living with their disabilities and their accessibility needs. Likewise, I wanted to understand what was preventing these changes from taking place, and as such focused on the organisational view of accessibility as well. Bridging the divide

between disabled visitor and service provider, as Capitaine (2016) had done, was the only way I could see to truly address the problem of inaccessibility for people with hidden disabilities.

Numerous academic sources (Mullins and Preyde 2013; Figueiredo et al. 2012; Blichfeldt and Nicolaisen 2011; Burns et al. 2009; Shaw and Coles 2004) and best practice guides (Kids in Museums 2018; Heritage Lottery Fund 2012) encourage speaking directly to disabled people to understand their perspectives and to learn from them. If it is agreed that speaking with disabled people is the best avenue, why are so many places hesitant to do so? In examining the literature, there are potentially several reasons offered as to why many places still are hesitant to engage in this kind of research with disabled people. A particularly salient reason as outlined by the Office for Disability Issues (2010, 17) is that people are afraid of making mistakes with disabled visitors and thereby making the situation worse. Although no staff members expressed their fear in these terms, I believe that this was at the heart of many of their comments regarding not knowing how to help (Appendix G 1.1, 3.1). Staff and volunteers understood they needed to explain the physical barriers of their site to a wheelchair user, but should they offer, for example, a seat to a healthy-looking young woman? They do not 'look' disabled, and staff members were hesitant to offer assistance and potentially embarrass – or even offend – a nondisabled visitor.

Multiple articles, written by both academics (e.g., van Jaarsveldt and Ndeya-Ndereya 2015; Cooper 1994) and disabled people (e.g., Weinstein 2021; Iezzoni 1998), discuss the paralysis that nondisabled people often experience when faced with a potentially uncomfortable interaction with a disabled person. Authors van Jaarsveldt and Ndeya-Ndereya (2015, 205) examine attitudes towards disabled students by university lecturers. A wide variety of attitudes are present, but in particular, "one lecturer, for example, removed a theme relating to visual analysis of literature from the curriculum so as not to offend a student with a visual impairment." Rather than risk an uncomfortable situation with a disabled student, the lecturer removed an entire lesson from a class. This avoidance robbed the students of an interesting class discussion, but also robbed the lecturer of an opportunity to better understand inclusive classroom etiquette.

Iezzoni (1998), immediately following a discussion of being professionally invalidated by a fellow medical doctor, discusses how "political correctness" has actually made polite encounters more emotionally fraught. A wheelchair user herself, she writes (1998, 663):

> Heightened semantic sensitivities undoubtedly chill some efforts at conversation with people who have disabilities. Our conversational partners are afraid of offending. Although I appreciate these difficulties, I believe they are quickly transcended by expressions of mutual respect and genuine interest, even if awkwardly phrased, and simple actions (for example, sitting down to be on the same eye level).

I found this same fear in the staff I interviewed. They were unsure how to approach the subject of disability and accessibility with visitors who could potentially benefit from such conversations, simply out of the fear of offending them.

Iezzoni's point about language is particularly interesting to me. Although she wrote her article in 1998, her argument is even more relevant today. In the decades since her article, the debate between "person first" and "disability first" language has only become more pronounced. I discuss this debate in Chapter 1, as well as my use of "people with hidden disabilities" based on the preferences of my participants. In many ways, disability studies has been overwhelmed by semantic debates. Although the linguistic framing of disability is important, as it shapes how a person or society views disabled people (Corker 2007; Harpur 2012b), it is also important to move past this particular debate. It creates the politeness paralysis that Iezzoni (1998) describes, or worse, it creates the over-compensation that van Jaarsveldt and Ndeya-Ndereya (2015) describe, neither of which help to dismantle barriers to accessibility.

Encouragingly, the National Trust is attempting to bridge the divide between semantic discourse and practical implementation. In July 2020, their new Strategy for 2025 was published, changing their motto from "forever, for everyone" to "for everyone, for ever," as previously discussed in Chapter 6. The semantic implications of this word change are enormous. Instead of focusing primarily on preservation, there is a new focus on the people aspect of their sites. On the webpage announcing the new strategy, the National Trust writes "underpinning this [motto change] is our

renewed commitment to diversity and inclusion and playing our part to create a fair, equal society, free from discrimination" (National Trust 2021c). There is still a heavy emphasis on environmental responsibility, but there is also an emphasis on increasing accessibility. Digging deeper in the brand strategy document they released, there is little additional information about their access strategy, other than "we'll make our places better for people who need support to access them, working through partnerships and testing new approaches" (National Trust 2020, 17) and a case study side-bar about monthly handling sessions for people with dementia and their carers at Wimpole Farm.

However, on the National Trust website, they included a 2021 update on their commitment to inclusion and diversity (National Trust 2021f). Reading through this page, it is clear that "access" is more than accessibility, and rightly so. Access to heritage is an issue related not only to disability, but also to ethnicity, LGBTQ+ identity, gender, age, and economic situation. The National Trust, through this renewed commitment, is attempting to address all of these matters. They include a list of positive, measurable, practical steps they have taken to address the inequality that has existed in the organisation before. Relevant to my research is the note that the National Trust has "continued to deliver training on Everyday Inclusion, and developed training for Recruitment and Disability Awareness" (National Trust 2021f). Without embedding the practical step of training, the change of phrasing would be little more than an act of lip-service to the communities they are trying to reach, including disabled people.

Although they have not introduced new mottos, my other case study sites are equally eager to implement new accessibility measures. During my observations, it was clear to me that there is a culture of accessibility embedded within their operations. At Abbey House, the education officer doubles as an accessibility officer. All the staff members I spoke to knew the accessibility limitations of their site, but also the tools they offer to mitigate these barriers (Appendix G 1.1). During my very first meeting with Mary, where I invited Abbey House to be one of my case study sites, a flier for a new exhibition at a different LMG site arrived. Mary, along with the education/accessibility officer, critiqued the design of the flier, saying that they had broken several style guidelines that had been put in place specifically for

accessibility. Although this does not reflect well on the wider LMG culture, it does illustrate how accessibility permeates every aspect of Abbey House. Likewise, at Barley Hall, accessibility is now considered in each decision that affects the visitor experience. The development of the COVID-19 video, discussed in Chapter 6, is an example of the embedded culture of accessibility. I cannot speak to how long it took for Abbey House to create this culture of accessibility, but from my own experience at YAT, it has taken several years for the organisational culture there to shift towards a more inclusive mindset.

As previously discussed in Chapter 8, Mary (Abbey House) and Maggie (Barley Hall) were both enthusiastic about the inclusions of maps and personal interpretation boards (Appendix G 1.3; 2.3). Mary commented that Abbey House had intended to produce maps, but based on my participants' suggestion, they would make the map a higher priority (Appendix G 1.3). Likewise, Maggie revealed there had been discussions of removing the map from circulation, but based on feedback from my participants as well as the front of house at Barley Hall, they would keep the maps (Appendix G 2.3). I provided her with the feedback that Teagan had shared with me, and Maggie agreed to pass these suggestions along as well.

Additionally, Maggie informed me that Barley Hall formerly utilised personal interpretation boards several years ago, but when Barley Hall was refurbished in 2011, these boards were replaced with the larger wall-hanging text panels (Appendix G 2.3). However, she was excited to hear how popular these smaller boards were amongst my participants and would speak to the interpretation team about bringing them back into circulation in future exhibitions. She also intended to speak to the travelling exhibitions team about incorporating smaller boards into their exhibitions.

Although I was unable to present my research directly with Treasurer's House, their reaction to the banister is in keeping with Abbey House and Barley Hall's attitude. Once the issue was noticed, they remedied the problem. Additionally, the rebranding of National Trust to "for everyone, forever" is another step towards more accessible, inclusive sites. All three case study organisations demonstrated gaps in disability awareness, but more importantly, they demonstrated a willingness to fill these gaps in order to better welcome disabled visitors.

## 10.5. Summary.

In examining all the evidence that I have collated through my interviews and site visits with participants with hidden disabilities, as well as my observations at case study sites and interviews with staff members, it became clear to me that gaps in disability awareness informed every interaction and every barrier that was encountered. Active/passive accessibility and lack of communication both inform and are informed by gaps in disability awareness. It is only by consciously breaking the cycle of this ignorance that my case study sites have been able to move forward, implementing measures to increase accessibility at their sites for visitors with hidden disabilities.

In the next chapter, I reflect on these lessons and discuss where I hope my research will lead next, as well as potential avenues of further investigation that would benefit both disabled visitors and heritage sites.

# Chapter 11 – Conclusion.

The aim of this research has been to understand the accessibility needs of people with hidden disabilities as well as the organisational barriers that prevent these needs from being met. As a heritage archaeologist working within the sector, as well as someone with hidden disabilities, I never believed that my participants' accessibility needs were complicated, nor did I see the organisational barriers as being insurmountable. Indeed, at the outset of my research, I believed that the answers to disabling barriers would likely entail small adjustments that took little to no monetary investment on the part of the organisations.

The truth is more complex than my original assumptions. True, the accessibility needs of my participants are more uniform than I expected, in that many of the barriers they encountered were consistent across multiple disabilities. These included confusing layouts, poor lighting levels, and forced communal reading, all discussed in Chapter 8. Additionally, the solutions and suggestions they offered – particularly maps and handheld interpretation boards – mostly entail small adjustments that could have profound, positive impacts on visitors, disabled and nondisabled alike, without being too costly. The maps in particular are a low-cost solution, as they require time to design and a cost to print, but little else. Indeed, Barley Hall found the cost so minimal that, once their usefulness to visitors had been proven through visitor and staff feedback as well as feedback from my research, they kept the maps, despite initially seeing them as a temporary COVID-related measure. Abbey House and Treasurer's House likewise had planned to introduce maps, and thanks to the recommendations from my research, Abbey House intends to accelerate these plans.

The organisational barriers, however, have proven to be more significant than I expected, particularly around lack of dialogue as discussed in Chapter 9. It is no small task to change how staff interact with each other, especially when so much time and effort is spent on training staff members to interact with visitors. Not to imply that this training is unimportant – in fact, I recommend more comprehensive training for public-facing staff members, particularly including awareness of hidden

disabilities. However, the lack of dialogue between staff teams and especially between staff across institutional hierarchies presents a significant barrier to implementing better accessibility measures at heritage sites.

Additionally, the pervasiveness of gaps in disability awareness has been startling for me, as discussed in Chapter 10. Such gaps are demonstrated in multiple ways at my case study sites. From the beginning, there was a lack of awareness as to what barriers visitors with hidden disabilities would encounter at these sites, with an assumption on the part of management that visitors with hidden disabilities would require large, resource-intense accessibility tools in order to enjoy their visit. More worryingly, at times, my case study sites adjusted their visitor experiences in ways that unfairly impacted disabled visitors, such as Treasurer's House bannister issue and the introduction of guided tours as the only means of experiencing Treasurer's House. Although these examples do not represent insurmountable obstacles, it will take time to reveal additional gaps beyond what I have uncovered through this research. Recall how Pfeiffer critiqued the ICF (2000, 1082), saying that what was needed was not another dictionary of impairments but rather a "philosophical revolution to change the dominant values of worldwide society." Perhaps uncovering and educating heritage organisations around gaps in disability awareness is the revolution he is looking for? If so, then how can such gaps in knowledge be challenged and overcome?

As demonstrated by my interviews and site visits with my participants, gaps in disability awareness must be challenged through inquiry and curiosity. This means asking disabled people not only about their experiences within museums and heritage sites, but also about their everyday lived experiences, particularly as hidden disabilities are known to have different symptoms from day to day. Indeed, my own research is one step along the path. But also, challenging gaps in knowledge means a great deal of reflection is necessary for heritage organisations to understand their own short-comings. Remember that in the social and human rights models of disability (discussed in Chapter 1), it is society that disables an individual. Therefore, we must consider the fact that heritage institutions themselves may be disabling their visitors, and hence it is the responsibility of those institutions to dismantle barriers with input from their visitors.

## 11.1. Reflections.

The world I originally designed my research in was not the world that I conducted my research in, nor is it the world in which I now publish my results. Embarking upon doctoral research is inherently fraught with uncertainty, but when I began in 2018, I could never have foreseen the fundamental, global change that would be the COVID-19 pandemic. However, as I discuss in Chapter 7, I believe the pandemic presented opportunities that likewise I never could have foreseen. Additionally, my own supervisory team changed in ways that I could not have foreseen - one person retired, another left academia for a new job, and unfortunately, one passed away. A great amount of intellectual agility and sensitivity was required on my part to not only adapt my research methodology but also to incorporate the substantial changes that took place within my personal sphere, the heritage industry and the world at large. I can now reflect upon the longer-term implications of COVID-19. Not only are people still being infected with COVID-19, Long COVID is a significant worry. Teagan experienced Long COVID, and although the primary symptoms have ended, she is still concerned she may be experiencing neurological damage from the illness. Additionally, deaths from COVID-19 may have declined, but infection rates are not declining at the same rate.

During a personal conversation with Dr Heather Smith in July 2021, she observed that as places were opening back up after lockdown, disabled people were becoming more isolated. Disability advocates have likewise pointed out that as people are moving back to "normal," they are leaving the digital spaces that had become so ubiquitous during the height of the pandemic (Shakespeare et al. 2021; Taylor 2021; Pring 2020). By Autumn 2021, the UK Government was urging people to return to their offices instead of working from home and facemasks were no longer mandatory. Even in 2022, there was a wide variety of working arrangements, but fully remote working had fallen to 14% (Office for National Statistics 2022).

To make matters worse, COVID-19 still represents a very real threat for disabled people. Not only are they still at a higher risk of developing potentially fatal complications if they catch the virus (World Health Organization 2021c), medical facilities and staff are under a great amount of pressure thanks to the rising cases

(Triggle 2021). This pressure has meant that other medical services have been scaled back to accommodate more COVID-19 patients and disabled people are bearing the brunt of it, having their regular, necessary appointments rescheduled or cancelled entirely (British Medical Association 2021). None of this considers the additional increase in mental health issues (Abbott 2021; Mental Health Foundation 2021). Studies into the pandemic-related mental health crisis examine the whole population, not only the disabled population (Talevi et al. 2020; Usher, Durkin, and Bhullar 2020), so it is difficult to determine the exact extent of the impact on disabled people, but it is a safe assumption that they are at least as impacted as the rest of the population.

Shifting governmental restrictions around COVID-19 have meant the visitor experience at my case study sites has been constantly evolving, even as I am handing in this thesis. The COVID-related changes at my case study sites have been a direct result of governmental guidelines and do not necessarily consider visitor feedback, particularly disabled visitor feedback. Because these changes were a result of governmental guidelines, I believe many sites were eager to undo these changes once the guidelines were removed. During the summer of 2022, when it seemed as if the COVID-19 restrictions would soon end, there was discussion at these sites about reverting back to the pre-pandemic experience wholesale without considering the benefits of any of the alterations they had made in the face of the pandemic. At Barley Hall, management originally intended to return to their pre-pandemic layout and to remove maps of the site. As testified to in Chapter 8, many disabled visitors found it difficult to navigate Barley Hall with this layout and previous lack of maps. Initially, no consideration was given to how these two changes had turned into accessibility measures – another example of a gap in disability awareness. Worse, there are some cases where disabled people's experience is not only forgotten but ignored entirely. I discussed the City of York Council's decision to remove Blue Badge parking spaces from the city centre during the pandemic in Chapter 2. In late November 2021, the Council voted to make the ban permanent, citing a desire to allow for appropriate social distancing and also to protect public safety from "hostile vehicle attacks" (BBC Yorkshire 2021), despite repeated protests from disabled people highlighting the discrimination inherent in this particular ban.

Indeed, the York Disability Rights Forum is planning on launching a legal challenge to this ban, citing discrimination (Walton 2021).

As seen in the Blue Badge Ban example above, decisions are being made that affect disabled people without any input from them. "Nothing about us without us" has been the motto disability rights advocates in the UK have rallied behind for decades (Werner 1998), and yet the message still has not been absorbed by wider society. My research has been an attempt to address this gap, to include disabled people and their expertise at the heart of the visitor experience at heritage sites in the north of England. I have found it an incredibly enriching experience, and although I believe the themes uncovered in my research have implications that can change the heritage sector, I particularly want to highlight the importance of communication, and especially dialogue, within organisations. I have been fortunate that my case study sites and the organisations that run them are committed enough to examine the barriers embedded within their structure. For example, in 2020, the JORVIK Group was awarded the Accessible and Inclusive Tourism award from Visit York (Jefferson-Brown 2020). During the ceremony, the announcers spoke of how there was no short-list for this award, unlike the other award categories, as there was only one competitor, and that was the JORVIK Group.

Addressing accessibility through physical alterations, particularly active accessibility measures, does not solve the deep-rooted ableism that most people grow up with and may never question. In the end, my initial hypothesis was correct: better accessibility need not be expensive or intrusive. Better accessibility requires thoughtful consideration and introspection on an organisational level. It is not enough to ask disabled people about their experience and the barriers they encounter – organisations must examine how these barriers were put in place to begin with. They need to involve staff members at every level, and they need to listen to staff members at every level. Only with open communication and true dialogue, like I saw at Abbey House Museum, involving everyone that accessibility touches, disabled and nondisabled alike, will lasting, sustainable change be made.

### 11.1.1. Reflections on Abbey House Museum.

At Abbey House, there is no doubting their commitment to increasing accessibility for their visitors, which I discuss in Chapter 5. Likewise, their unique egalitarian staff structure creates a supportive environment where any suggestion regarding accessibility is given due consideration. Communication between teams, especially between front of house staff and management staff, fosters discussion around accessibility measures, which in turn benefits disabled visitors. This culture of communication is seen in the relaxed Father Christmas sessions, discussed in Chapter 8, where a front of house staff member suggested these relaxed sessions in direct response to a particular encounter with a disabled visitor. Not only did management enact this suggestion, they also took the suggestion a step further by turning the hand dryers in the toilets off during other inclusive events. In this way, discussions between multiple different groups (i.e., visitor/staff, staff teams, hierarchical) lead to more accessible, inclusive visitor experiences.

Because of examples like the relaxed Father Christmas sessions, I believe that where Abbey House falls short is not in their lack of communication but rather in their gaps in disability awareness. Mary freely admits that her staff are unsure how to help visitors with hidden disabilities, something that is confirmed in my front of house staff interviews discussed in Chapter 9. Staff members can – and do – make their own observations, but to my knowledge, they conduct little to no internal research themselves with disabled groups. However, they have an active disabled community around them in Leeds. Local disability organisations provide a link between the museum and disabled people themselves, and utilising the methodology laid out in my thesis, I believe they can connect directly with disabled visitors to dismantle more barriers within Abbey House.

### 11.1.2. Reflections on Barley Hall.

Barley Hall has similar strengths in their staff communications. Although the staff hierarchy is not as egalitarian as at Abbey House, there appears to be an obvious level of respect and trust between staff teams. However, because of the layout of Barley Hall and the positioning of front of house members, there is limited contact between staff and disabled visitors. In their post-pandemic layout, which I discuss in

Chapter 7, visitors encounter staff members at the beginning and end of their visit. Throughout the museum, visitors are left on their own, meaning any barriers they encounter are never witnessed by staff members. In turn, Barley Hall relies on self-reporting of difficulties from disabled visitors to expose any barriers to accessibility – indeed, they even mention on their website that staff "will be happy to… note any suggestions you have" (The JORVIK Group 2021b). However, as discussed in Chapter 8, many of my participants do not wish to disclose their accessibility needs. Their desire for nondisclosure leads to the necessity of passive accessibility measures, which must be embedded into the design of an exhibition to allow for a more inclusive experience. If Barley Hall staff are not available throughout the museum, they cannot observe any difficulties that visitors may have. The positioning of Abbey House staff members throughout the museum was integral to their observations which led to accessibility measures like the relaxed Father Christmas sessions. There is no potential for such observations at Barley Hall, and indeed, the only accessibility-related suggestion that front of house staff members could offer is regarding subtitles on the video that plays beside the admissions area.

In this way, I believe the area most in need of attention at Barley Hall is the limited communication between visitors and staff members. There is potential for volunteers to fill this critical role, as they are normally stationed within the museum itself (see Chapter 9) and therefore can observe visitors interacting with the museum itself and any barriers therein. I was unable to interview any Barley Hall volunteers, discussed in Chapter 6, so I am unsure of how they sit within the team structure. Based on my own experience of volunteers within the wider JORVIK Group, they are similar to Treasurer's House volunteers in that they are isolated from other teams. If Barley Hall volunteers are thus separated from other teams, a similar problem to Treasurer's House may arise: the lack of communication between teams means that there is no discussion of barriers and potential solutions, rendering the communication between volunteers and disabled visitors less than impactful.

I would also strongly encourage the JORVIK Group to rethink their desire to revert back to the pre-pandemic layout. At the time of handing in this thesis, the layout had not reverted, but since the lifting of restrictions in early 2022, there has been talk amongst senior management about changing the layout. I cannot ascertain any

reason for this aside from the original layout being more familiar. I would therefore recommend that they conduct visitor research to better understand the impact of the layout on visitor experience - my own data suggests that keeping the layout in its current form would be beneficial to all visitors, disabled and nondisabled alike.

### 11.1.3. Reflections on Treasurer's House.

Turning to Treasurer's House, I believe lack of communication is a significant barrier to any changes related to accessibility at this site. This lack of communication is present in all types of relationships that I examined in Chapter 9, and I vividly remember my own sense of frustration during my observations at how little staff teams interacted with each other. My interviews, discussed in Chapter 9, reveal a property full of people who wish to give all visitors, disabled and nondisabled alike, the best experience possible. However, with little interaction between the staff members themselves, there is great inconsistency in how this visitor experience is delivered. The inconsistency cannot be solved through training alone, although I do recommend a more holistic training agenda that encompasses hidden disability awareness. There must be a culture change within the property, where there is more contact and communication between teams, engendering the trust that was so evident at Abbey House and Barley Hall. Only by empowering staff members further down the staff structure can meaningful, inclusive change happen.

I was fortunate enough to speak again with Dr Heather Smith, Equity Officer for the National Trust, about some of these concerns in February 2023. While she was unable to speak to specific issues at Treasurer's House because she is a national officer rather than a local one, she did provide great insight into what the National Trust is doing to address the institutional barriers that many disabled people encounter. With the advent of their "For everyone, forever" campaign, there has been a great amount of effort put towards realising this goal, including increasing accessibility at their properties. Their EDI strategy, which I discuss in Chapter 4, mentions accessibility in many of their targeted actions. Additionally, they have developed the "Everyone Welcome" strategy to encompass all the work that they will do across the Trust. In explaining this new strategy, Heather made it clear that accessibility was built into every aspect and every action. This included updated e-learning for staff and volunteers that included disability awareness, improved

sensory tours, bringing in external experts (both disabled people themselves and accessibility consultants), and several new pilot projects to test out technologies to increase the accessibility of their properties. Accessibility is being built into all projects from the very beginning, embedding passive accessibility into the visitor experience, something that I recommend in Chapter 8. They are also taking steps to address gaps in their disability awareness, which I discuss in Chapter 10, through their e-learning scheme and partnering with external experts.

Additionally, and perhaps most importantly, funding has been set aside specifically to help properties make accessibility improvements. Indeed, new "accessibility standards" are being introduced across the Trust at Bronze, Silver, and Gold levels, and each property must agree to make improvements according to these levels. Bronze improvements are small, mostly inexpensive improvements, such as ensuring that induction loops are installed at all communication points. Silver improvements are slightly more expensive and more labour intensive, such as regularly scheduled BSL tours at a property instead of providing them on-demand. Gold improvements take considerable investment, such as the installation of a Changing Places toilet. The funding stream then is an extremely important aspect of this commitment to improving accessibility so that each property can analyse what would best suit their location and receive support to enact those changes.

It is clear to me that there is a cultural shift taking place within the National Trust, one that embeds accessibility and disability awareness throughout all aspects of their operation and will therefore better benefit visitors to National Trust properties. There is also ongoing work to improve communication across staff hierarchies and to empower more junior staff to suggest improvements, something I discuss in Chapter 9. The new "accessibility standards" scheme in particular gives each property a chance to find solutions that work best for them, as accessibility is never a "one size fits all" - neither for the sites nor for disabled people themselves. Additionally, because Heather was a member of my Thesis Advisory Panel, she has been involved with my research from the very beginning and had this to say about how my research has informed the National Trust EDI strategy:

> The heritage sector as a whole has much more to do to understand how to provide
> the best welcome to people with a broad range of disabilities and needs. This thesis

topic confronts this issue, led by testimonies from people with lived experience and evidence from their own visitor experience. This is by far the best way to learn and to understand what our environments are like and how we can improve. For our own part, this thesis arrives at a time where we are ripe to make these improvements. I have been, and will continue, to share the overarching learning across our places as a catalyst for our own commitment to Everyone Welcome for people with invisible disabilities, for whom we create very visible barriers both physically and emotionally. (Smith 2023)

## 11.2. Limitations of this Research.

Naturally, there are significant limitations to this research. Any project, particularly a doctoral research project, can only represent a small section of a larger picture. Below, I reflect on these limitations and also their impact on the final conclusions of this research.

### 11.2.1. Disabilities Represented.

Given the nature of this research, only a limited number of people could participate and even then, for a limited period of time. As discussed in Chapter 5, disabilities - and hidden disabilities in particular - can vary from day to day. Whilst I tried to account for this amongst my participants by having them explain the impacts of their conditions rather than relying on my own observations, they still represent only their experiences. Many of them also acknowledged that they would experience worse symptoms and deteriorating health as they aged (see Chapter 6), further implying that even amongst my participants, I was unable to capture the full range of symptoms and barriers that my participants would experience.

Additionally, there is a limited number of hidden disabilities included in this research. As discussed in Chapter 1, "hidden disabilities" cover an enormous range of conditions. One research project would never be able to account for all of these conditions, hence the propensity of most surveys to focus solely on only one or two conditions. I wanted my research to strike a balance between a wide variety of hidden disabilities and a deep analysis of their implications in museum and heritage accessibility, hence why I selected a small number of participants and developed a methodology to more thoroughly examine their experiences.

As I discuss in Chapter 5, I utilised social media and an email campaign through the University of York to recruit participants. As a result, the overwhelming majority of my participants are women who are under 40. Whilst I do not believe that this has skewed results at all, I would be interested to hear from people with hidden disabilities who do not fit this particular demographic. I would also have preferred a wider variety of hidden disabilities. Again, I do not believe my results have been skewed as my findings reflect systemic issues not specific to any particular disability, but I would be interested to include more varied experiences.

The initial design of this research included a linking online survey to gather additional data regarding accessibility at museums and heritage sites. The plan had been to distribute this as widely as possible to capture the voices of as many people with hidden disabilities as possible and link these wider trends to the deeper analysis of my participants. However, I decided against this method for several reasons. Most importantly, I felt that such a survey depersonalised these experiences. The point of my research was to elevate the experiences of disabled people, and an anonymous online survey necessarily detached their experiences from their identity. Indeed, a common drawback of online surveys is the conflation of privacy and anonymity, meaning that a right to privacy is seen as requiring complete anonymity (Evans and Marthur 2018; Siva et al. 2019; Andrade 2020). As discussed in Chapter 5, my participants took their identity as people with hidden disabilities very seriously and did not want that identity taken away.

Additionally, the survey would have asked disabled people to reveal potentially triggering memories without any support or care given to their wellbeing. Buchanan and Hvizdak (2009) and Shaw et al. (2020) both emphasise the responsibility of the researcher to ensure vulnerable participants - and recall from Chapter 5 that my participants are considered 'vulnerable' due to their disabilities - are not further harmed, physically or emotionally, by taking part in research. As Liamputtong puts, "researchers delve into the private worlds of the participants and it is likely that their private worlds will be invaded" (39). I took my duty of care with my participants very seriously, ensuring that they felt safe and comfortable at all times during my research. There was no way to provide that same level of care to potential online

participants. I perceived it as harmful to ask disabled people to provide their negative experiences without also providing a space for them to work through these experiences and any emotions they stirred. As I felt a personal obligation to ensure my research did not exploit disabled people's experiences, I could not in good conscience continue with an online survey that did not allow me to develop a trusting relationship with these participants.

During the course of designing my methodology, I also came to the conclusion that qualitative data would be far more effective than quantitative for my research. As Warren puts it, qualitative research "is more concerned with being attuned to who is being travelled with, so to speak, than with setting out a precise route for all to follow, as in survey research" (2002, 86). Every disabled person has a different experience with disability, and because I wanted to focus on personal experiences, quantitative data did not fit into my overall research goal. As discussed in Chapter 5, qualitative research would allow me to examine these barriers with a more nuanced understanding while also allowing me to further query responses and incidents as I worked through the data. Rather than a wide but shallow analysis, I took a narrow but deep approach to uncover the themes discussed in Chapters 8-10.

Above all, accessibility was a deciding factor in determining that an online survey would not provide enough relevant data to be academically meaningful. Studies have shown that disabled people are more financially disadvantaged (Koning and van Sonsbeek 2017; Emerson et al. 2021), and this includes access to the internet (Pilling, Barrett and Floyd 2004; Blank 2013). Additionally, many of my participants use some kind of screen reader or assistive technology - online survey websites are not necessarily created with these technologies in mind, again excluding potential participants. An online survey would inherently exclude a number of people with hidden disabilities due to these financial and technological reasons alone. Research has also shown that although the internet was originally seen as a way to break down barriers, it has only reinforced a great many of them, including the exclusion of disabled people (Watling 2011; Scholz, Yalcin, and Priestly 2017; Tsatsou 2021; 2022). Social media, one method for recruiting participants to my research, is by no means perfect: many of these platforms treat accessibility as an afterthought or

additional user burden (Kent 2014; McMillen and Alter 2017) - and therefore I wanted to limit its use as much as possible.

In the end, a linking online survey presented enough barriers to participation that I felt it would detract from the overall research project. There certainly would have been benefits to a survey of this kind, especially in gaining a wider perspective and potentially including more hidden disabilities, but the survey would also be better suited to a different research project.

## 11.2.3. Organisational Understanding.

There are, of course, numerous limitations to this research in terms of organisational understanding. I only examined barriers at three case study sites and although I chose three sites with three different types of heritage organisations (see Chapter 5), they do not represent the entirety of the museum and heritage industry. How would communication (or the lack thereof) manifest at a heritage site staffed fully by volunteers? What passive accessibility measures could be enacted at an open-air museum? What barriers would be present in a more traditional white box museum space?

Additionally, I chose my case study organisations knowing there was a certain level of commitment to accessibility already. However, not all heritage organisations recognise the importance of accessibility and inclusivity – what systemic barriers are present in such places? How does one even begin to implement accessibility measures at a site that is more openly hostile to these changes? Features such as maps and personal interpretation boards can be framed as useful tools without highlighting their benefit to accessibility, but should they?

Even within my case study sites, there are limitations to my conclusions, which I will discuss further now.

### 11.2.3.1. Site Visits.

I also acknowledge that I have limited evidence from my participants at two of my case study sites. Again, I discuss this more extensively in Chapter 7, but the advent of the COVID-19 pandemic meant that, although I had completed the site visits with

my participants to Treasurer's House, I had very limited opportunities to take my participants to Abbey House and Barley Hall. As above, I do not believe that my ultimate findings would have altered, but I would have preferred a more balanced picture of all three case study sites. I would also have liked to incorporate more evidence from Abbey House and Barley Hall in my analysis, showing barriers such as low lighting (see Chapter 8) to be universal rather than a problem specific to Treasurer's House. Whilst I did begin to observe similarities at Abbey House and Barley Hall, particularly in relation to matters of communal reading (Chapter 8), I would have preferred to find stronger parallels.

### 11.2.3.2. Site Observations and Staff Interviews.

My understanding of organisational barriers is not as strong as I would have preferred. Although I do not doubt that lack of communication across an organisation is the most significant barrier to implementing accessibility measures, I was only able to observe for myself this difficulty at one case study site. Based on the observations I was able to conduct, as well as the interviews with staff members, I believe that Abbey House and Barley Hall do not have the same challenges as Treasurer's House, but I would have preferred more time to fully understand how their teams interacted. Additionally, I would have liked to interview a larger sample of staff members and volunteers at each case study site, but the challenges of COVID-19 made this impossible. Again, I do not believe my ultimate findings would have changed drastically, but I believe that I would have significantly more evidence to support my themes, particularly lack of communication, as explored in Chapter 9.

### 11.2.3.3. Documentary Analysis.

In Chapter 5, I explain my use of Critical Discourse Analysis to understand the subtler power dynamics at work. Although I did apply this theoretical structure to all interactions I observed and participated in, I am curious what CDA as applied to the documents and policies of my case study organisations would reveal, particularly in light of NT's motto change from "forever, for every one" to "for every one, forever." The linguistic change seems to create more inclusion, and my initial reading of the brand strategy supports this idea, but a more thorough analysis is required to understand the depth of cultural change that such a document can produce.

## 11.3. Links to Wider Research.

In many ways, my research conclusions mirror the conclusions of recent EDI work, as discussed in Chapter 4. Shifting from active to passive accessibility and embedding passive accessibility (Chapter 7) into practice parallels some of the EDI work done to identify and remove barriers to participation for people with other protected characteristics. In order for EDI strategies to succeed, the entire organisation must be encouraged at all levels of responsibility - something that can only be accomplished through open communication (see Chapter 8). Finally, it is not enough to be inclusive, organisations must actively work to be anti-discriminatory and dismantle institutional ideas that unconsciously exclude people. Similarly, it is not enough for organisations to acknowledge that they have inaccessible areas: they must work to identify the gaps in their disability awareness and then to educate themselves and their staff to address these gaps (Chapter 9). They must actively become anti-ableist, not merely "accessible."

Looking at more specific themes within the EDI landscape, my research specifically highlights other research going on in the area of the impact of hidden disabilities and of inclusive cultural participation.

### 11.3.1. Impact of Hidden Disabilities.

As mentioned above, because of the nature of this project, I was not able to examine the long-term effects of hidden disabilities on my participants. However, I did not think this examination would be particularly relevant, as there is already much research on the physical effects of hidden disabilities, both short-term and long-term. Multiple authors have already examined the physical impacts of arthritis (van Vollenhoven et al. 2019), depression (Hildrum et al. 2008), and hypermobility and EDS (Simmonds and Keer 2007), among other hidden disabilities. Much of this research focuses on the negative effects that these conditions create for those who are diagnosed, but I was more interested in the barriers that individuals face and how to remove these barriers. The differences in my research compared to much of this other research is rooted in the disability model employed: much of the impact research utilises the medical model of disability, positioning the problem within the disabled person, whereas my use of the human rights model positions society as the

disabling factor. There is a trend within the past few years to shift to a social model or a human rights model, particularly in the social sciences (Lawson and Beckett 2020; Waddington and Priestley 2021), but most research situated within health sciences medicalises hidden disabilities. As I discuss in Chapter 1, this is not inherently problematic: research into more effective treatment of these conditions, especially physical conditions like arthritis or EDS, is invaluable for increasing quality of life in people with these hidden disabilities. However, this medicalisation does not remove societal barriers, nor does it promote social inclusion.

Recall that the CRPD lays out in Article 30 that disabled people have the right "to take part on an equal basis with others in cultural life" (United Nations 2006, 22). The importance of my research is in examining how to dismantle these barriers and advance this right. As I discussed in Chapters 1 and 6, all of my participants experience real medical implications from their disabilities that I do not wish to belittle or dismiss. Therefore, I view my research as complementary to this more medicalised research, allowing a more holistic, whole-life approach to increasing quality of life for people with hidden disabilities.

### 11.3.2. Inclusive Cultural Participation.

There is also a large body of research examining inclusion in the wider cultural sector, including outdoor activities and sports. I reference Burns et al.'s research into barriers to participation in outdoor leisure activities in Chapter 3, but there are many more studies that examine inclusive engagement. For example, Ryuh et al. found that inclusive football - where children with and without intellectual disabilities (which they abbreviate to ID) played cooperatively on a team - showed "that [a] physical activity program which integrates children with and without ID can reduce the withdrawn behaviour and social distance of both typically developing children as well as children with ID" (2019, 701). In other words, these inclusive sports teams showed a positive wellbeing impact on both disabled and nondisabled children, as well as better attitudes towards disabled children on the part of nondisabled children (701). This agrees with Daruwalla and Darcy's research that showed more interaction with disabled people contributes to positive attitudes and reduced negative stereotypes of disabled people (2005), something I discuss in Chapter 3.

Critically, however, the relevance of these studies to heritage spaces is worth questioning, as rarely are heritage experiences repetitive, competitive activities.

Additionally, heritage spaces have been recognised as unique because of their connection to the past and what this connection means for people in the present. There is much research examining the benefits of interacting with heritage (Fujiwara, Cornwall, and Dolan; Sofaer et al. 2021; Power and Smyth 2016), and more research is being conducted aimed primarily at minority populations, including disabled people. Thomson and Chatterjee's work in particular examines the wellbeing benefits of object-handling in clinical settings (Thomson et al. 2012; Camic and Chatterjee 2013; Thomson and Chatterjee 2016), generally hospitals or care homes. Her research showed that participants experienced "improved wellbeing after the intervention, such as improved mood, calmed anxiety, or a feeling of enhanced confidence" (2013, 234). More recently, Sofaer and Gallou examined the role of visits to heritage sites on wellbeing during the COVID-19 pandemic lockdown, finding that "access to heritage sites reinstated a sense of normality and control over their actions" (2022, 29), something they sorely lacked due to lockdown restrictions. Again, I view my research as complementary to these previous investigations, as my research uncovers the barriers that keep people with hidden disabilities from participating in heritage, thereby preventing them from reaping the benefits of heritage that the other research highlights.

Despite the limitations of my research, I do believe that the thematic results from my research are relevant to a large cross-section of people with hidden disabilities and dismantling barriers to their participation in heritage and wider cultural activities. As I discuss in Chapter 8, nondisabled people too benefit from passive accessibility. Better communication will bolster EDI efforts, discussed in Chapters 4 and 9. Uncovering gaps in disability awareness, which I discuss in Chapter 10, also exposes unconscious biases and presents interesting opportunities to adapt and redesign experiences that are more inclusive.

Because my conclusions are more thematic, they present a higher-level view of the barriers present. Recall McKercher and Darcy's (2018) "Hierarchy of barriers to travel by people with disabilities" diagram from Chapter 3 - there are tiers of barriers,

with Tier 1 barriers being common to all people, disabled and nondisabled alike. The barriers I have uncovered in my research are largely in Tier 1, with "gaps in disability awareness" falling into Tier 2. Had I included more types of hidden disabilities or a linking survey, perhaps more barriers would have come forward, and other examples of passive accessibility would perhaps be highlighted, but the overall landscape would not have changed.

## 11.4. Next Steps.

In creating my methodology, I always intended for it to be adapted and re-used in future research. I welcome other researchers to elaborate on my approach, incorporating more types of disabilities to increase our understanding of accessibility for people with hidden disabilities. Additionally, and perhaps more importantly, I encourage more organisations to examine their own institutional roadblocks and query how best they can dismantle these barriers.

Personally, I intend to continue exploring the barriers to accessibility within heritage sites. As I discuss in Chapter 6, I am an employee at YAT and although I have moved away from my front of house role, I am still heavily involved in accessibility not only at our attractions, but across the wider Trust as I work to develop our EDI policy. Because of my background, there will be an emphasis on accessibility and inclusion of disabled people, building on the work I have already done within the Trust. However, there is an impetus within the Trust to widen our inclusiveness beyond disability inclusion, and I am leading the development of Diversity Champions within the Trust. These Champions will be advocates for underrepresented groups by helping to shape policies and suggesting initiatives for the Trust to become involved in.

Additionally, my links with my case study organisations have already proven fruitful, as I am in early discussions with both Leeds Museums and Galleries and National Trust to share knowledge and experiences that will benefit all organisations in becoming more inclusive. I have also connected with York Museums Trust, the other major heritage player in York, to similarly compare experiences and learn from each other, solidifying York - or at least its museums - as an inclusive place that welcomes

all visitors. I believe that strengthening connections between organisations in the sector like this will bring not only more ideas and insights to EDI, but also will spread inspiration and best practices more widely.

Most importantly, I have remained in contact with several participants – indeed, two of them are now my co-workers at YAT. They continue to challenge me in my assumptions regarding the accessibility of our attractions and our workplace routines, as well as what it means to be disabled.

Above all, however, I wish to remind those who are only beginning their journey into museum accessibility to not be overwhelmed. Changes cannot be made overnight, and small steps are better than none at all. As Ellie (Treasurer's House; anxiety, chronic vestibular migraines, depression, fibromyalgia – Appendix C 5.4) says:

> It's just little things that can make such a huge difference. And even for nondisabled people, visitors who don't have disabilities, I'm sure things like the lighting and making sure that fonts are legible are just as important [to their experience].

# Appendix A – Participant Interview Design.

This appendix contains the questions that I asked participants.

## 1. Pre-visit Interview.

### 1.1. Introduction & consent forms.

*After arranging our meetings, this is the first time I come to their home. I re-introduce myself and my research, making sure that they understand what we'll be doing and how I will be collecting data. Then I give them the opportunity to ask any questions before they sign the consent form, as well as take some general biographical information. This part is **audio recorded**.*

Hello, I'm Ashley, we've emailed a few times. Before we get started, I want to go over a few things just to make sure we're all on the same page. My research is looking at accessibility for people with hidden disabilities in museums and heritage sites, and you've been asked to be a participant because you have a hidden disability. As I mentioned, we'll have three different meetings: one now, so I can learn how you prepare for a trip, another one where we go to a museum – in your case, the _____ – and I'll have a basic outline for things we'll do, but by and large, I want you to lead that visit so I can understand how your hidden disability might affect your experience. After the museum visit, we'll go straight to a café or a park and have a chat about the experience as a whole. Then, a few days later, we'll have our last meeting where we'll talk about the museum visit we took together again, but also about other museums you've visited and how they compare. Does that sound alright?

I sent you a copy of the information sheet and the consent form, but I have copies right here for you to look over again. Before you sign the consent form, do you have any questions?

Fantastic, I have a few questions for you – and I want to emphasise, you are free to ***not*** answer these questions if you don't want to. You mentioned that you have _____. I've done a little research on them, but you're the expert, can you explain to me what they are? These are both conditions that you were born with, is that correct? Great – I'm asking because I can read any number of papers and books about it, but you have the lived experience, you understand what it's like to live with these conditions much better than I ever will, and I'm really interested in your take on how it impacts you and your activities.

### 1.2. Think Aloud practice.

*The Think Aloud technique has been shown to be a method that elicits mental processes to an observer in order to allow analysis of actions. It has also been proven that, with a bit of instruction and practice, the technique is even more effective. Ideally, it involves some kind of problem-solving activity, and I have them sort a collection of cards with photos of food on them, practicing the Think Aloud technique as they do it. This part is **not audio recorded** (but may end up being recorded simply for ease).*

For the most part, I'm just going to observe you going through the motions of preparing for a trip to the museum. I might ask some questions along the way, but the main thing I want you to do is something called the Think Aloud technique. Basically, you're going to narrate what you are doing and what you are thinking as you do something.

So, to practice this, I have a little activity for you. I want you to practice thinking aloud while you sort these cards into groups. It doesn't matter what the groups are, there's no right or wrong answer here, I just want you to practice thinking aloud while you sort the cards. Does that make sense?

*After a demonstration of sorting things (**not** using the cards but simply whatever is at hand), I have them then sort the cards into group, repeating the exercise until I feel satisfied they have had enough practice with thinking aloud.*

## 1.3. Trip preparation.

*This is the primary section of data that I am gathering. This may be "staged" in that the participant may have already done their website research or they may not be ready to prepare for the journey to the museum, but I still want them to simulate the actions so I can observe it. This part is **audio recorded** and **written field notes** taken during the interaction.*

## 1.4. Website research.

*There is not a set script for this section, but I observe how they plan and research a trip to the museum, including transportation arrangements. The participants use the Think Aloud technique they just practiced, with encouragement and prompting from myself if needed. Questions I am specifically looking to answer are:*
- *What information do they need?*
- *What websites do they check?*
- *What access tools do they use?*

## 1.5. Physical preparations & considerations.

*Again, this section does not have a set script but instead I observe how they prepare for a trip. This part can vary widely from person to person, depending on their disability and the severity of it. This also could be the most personally invasive, as it may involve medication or medical equipment, so care and discretion is used to determine what is and is not necessary in terms of data. Questions I am specifically looking to answer are:*
- *What specialist equipment or aids do they need?*
- *What eventualities do they plan for?*
- *How much time does it take to get everything together?*

## 1.6. Details for next time & wrap up.

*This section is far less formalised than any other section, but I am confirming our future plans, especially the date and time of our next meeting. I also make sure they have a way of contacting me (via email) if they need to change plans or have any further questions in the meantime.*

## 2. Site Visit.

### 2.1. Journey to site.

*I meet them at their home once again to travel to the museum with them, as I want to see what barriers and hurdles they encounter simply getting to a site. It may not be something that museums can directly control, but it may inform what information they can provide. There is no formal narration for this section and it is **not audio recorded**, though **written fields notes** are made. However, I am watching specifically for these things in each situation:*
- Via train.
  - Is there a problem with seating?
  - How is the staff interaction?
  - How well are things sign posted?
  - Is it easy to get from point A to point B?
- Via bus.
  - Is there a problem with seating?
  - How is the staff interaction?
  - How well are things sign posted?
  - Is it easy to get from point A to point B?
- What information does the museum provide?

*I also go over the points that I want to make sure they experience during the visit (see below for specific points).*

### 2.2. Semi-structured site visit.

*This is the main data collection section of the entire study. Based on a "mystery shopper" format, the visit is semi-structured, in that there are specific points that we visit, but for the most part, the participant leads how the visit goes. Having specific points allows for better comparison between participants, leading to more robust data analysis. These specific points are:*
- *Visiting a particular exhibition (Abbey House – Danger Zone; Barley Hall – Great Hall; Treasurer's House – Blue Drawing Room).*
- *Asking for help.*
- *Purchasing a small item in the shop.*
- *Toilets.*

*The mystery shopper format is divided into six main areas (finding the museum, entry and payment, museum experience, shop experience, team observation, and toilets) and in each area, there are the specific questions I am looking to answer.*

*This section is **audio recorded** and also has **written field notes**, as well as potential for digital photographs of relevant details. I also ask them at various points to engage in the Think Aloud technique that we practiced during our first meeting to understand how they are interacting with a display.*

## 3. Post-visit Interview.

*This takes place in a nearby café – somewhere that is removed from the site itself to give some physical distance between the participant and the site. In the case of the Abbey House*

*Museum, it is across the street at the Kirkstall Abbey gardens café. It is a semi-structured interview, so the conversation will not necessarily go from question to question, but I try to guide the topics to gather relevant data. It is **audio recorded** and may have **written field notes**.*

## 3.1. Visit audit.

### 3.1.1. The museum.

- Was it easy to find the museum from the street?
- Was it easy to find the entrance?
- Could you understand the layout of the museum?

### 3.1.2. The shop.

- How was the signage?
- Was there enough space to move around the shop?
- Could you navigate the shop?

### 3.1.3. The toilets.

- Could you find the toilets?
- Was the toilet clean?
- Was the toilet floor clean?

### 3.1.4. The staff.

- Was the team member able to offer appropriate help when asked?
- Did you feel welcomed at the museum?

### 3.1.5. The exhibits.

- How were the displays?
    1. Could you read the fonts?
    2. Was the colour contrast okay?
- How was the volume on the videos?
- Could you understand the stories and tales the museum told?
- How was the noise level?
    1. Were some places too loud?
    2. Were some places too quiet?
- How was the lighting?
    1. Were some places too light?
    2. Were some places too dark?
- Were there enough places to sit and/or rest?

### 3.1.6. Specific exhibition: Victorian Street (Abbey House)/Great Hall (Barley Hall)/Sitting Room (Treasurer's House).

- How were the displays?
    1. Could you read the fonts?
    2. Was the colour contrast okay?
- Could you understand the stories and tales the museum told?
- How was the noise level?
- How was the lighting?

- Were there enough places to sit and/or rest?

## 3.2. General questions.

1. What was your favourite thing about the museum (generally)?
2. What was your least favourite thing about the museum (generally)?
3. One good and one bad thing about the museum (related to disability).
4. Did any barriers jump out at you?
5. Were there any access tools that were helpful?
   - Could the museum provide anything to help?
   - Could the museum design into their exhibitions from the beginning (font, colour scheme, etc.) that might be more helpful to you?
   - Did you bring/use anything that you personally supplied?
6. How did the staff make you feel?
   - Did you feel you were treated any differently than other visitors?
   - Do you think you would be treated differently if your disability was visible?
7. Would you visit the museum again? Why or why not?
8. If you could tell the museum one thing regarding the accessibility of their site, what would it be?

*At the end of the conversation, I prompt them to think about other museum visits and how this one compares for us to discuss next time. I also confirm the details of our next meeting and check again that they have my contact details if they have any questions or concerns in the meantime.*

## 3.3. Journey back from site.

*This part of the journey should, theoretically, be similar to the journey to the museum, so I use this time to make a few written notes if needed and to build on my rapport with the participants. I also ask them if they would consider a return visit there as we part ways, now that they have had some time to soberly reflect on their visit. This is **not audio recorded** and **no written field notes** unless something unusual or extreme happens.*

# 4. Follow-up Interview.

*This meeting takes place ideally at their home again, but has the possibility to be a phone call or done via Skype or Google Hangouts, as it does not require physical interaction or observation.*

## 4.1. Recap of visit.

*After a brief welcome and small-talk catch up, I begin with a brief review of our site visit. This is to re-engage our rapport and to refresh the memory of the visit in both our minds. I ask confirmation questions, clarification questions, and follow-up questions based on our café chat and any other observations that have occurred to me upon reviewing my field notes and audio recordings from the visit. This section is **audio recorded** but **no written field notes** are taken.*

- They each mentioned one thing they would like to tell the museum.
- Their favourite aspect of the museum.
- They wouldn't return alone, but they may take someone there if they'd never visited before.

## 4.2. My questions.

*This, like the café chat, is a semi-structured interview. I guide the conversation towards these questions, but give the participants the opportunity to lead the conversation. This section is **audio recorded** but **no written field notes** are taken. Questions I am most interested in are:*

- How did you feel the next day?
- Did this museum remind you of any other museum you've visited? In good ways or bad ways?
- Do you think there are different expectations put on paying vs non-paying museums?
- If we had taken this trip on a "bad day" (for their disability), would it have changed anything? How?
- Do you consider yourself disabled?

## 4.3. Their questions.

*This section allows the participant to raise any questions or concerns they have about the project, the visit, anything I can generally answer. Also, if there is anything else they would like to discuss, they are given the opportunity to bring it up This section is **audio recorded** but **no written field notes** are taken.*

# Appendix B – Ethics Consent Forms.

This appendix contains the ethics consent form that all participants and staff members that I interviewed read and signed.

## Out of Sight, Out of Mind: Accessibility for Hidden Disabilities in Museums and Heritage Sites

## 1. What is the study about?

This study is about understanding the access needs of people with hidden disabilities in museums and heritage sites. To this end, the researcher wants to go through all stages of a museum visit alongside people with hidden disabilities in order to get their perspective. This initial pilot study is to trial the proposed methods of gathering data (i.e., through interviews and observations before, during, and after a visit to one of the case study sites) and to test the more practical aspects of the methods. It is being carried out by Ashley Fisher, a PhD student in the Archaeology Department at the University of York under the supervision of Dr Sara Perry. All practical aspects of the study will be carried out by Ashley. The case study sites are Barley Hall (York), Treasurer's House (York), and Abbey House Museum (Leeds), and the organisations that run these sites have agreed to participate.

## 2. How will the research be carried out?

Research will be carried by the researcher (Ashley) in various forms:
- Interviews.
- Observations.
- Site visits.

Data will be collected in various forms as well:
- Audio recordings.
- Written observation notes.
- Photographs.

**Please note**: photographs of the participants will *not* include identifying features, such as faces, though it may include other features such as hands. Voice recordings may be transcribed for the purposes of analysis and data accessibility.

All participation is voluntary, and participants are free to leave the study at any time. Where possible, contributions will be removed from the record if requested.

## 3. How will the research findings be used?

The findings from this pilot study will be used primarily to inform the design of the full scale study, which will involve the same data gathering methods (observations, interviews, and site visits) but with a larger sample size. However, some of the information gathered from the pilot may also be used in presentations, articles, or discussion in the full thesis. If it is used, all privacy measures will be taken to ensure anonymity.

## 4. How will my data be stored?

All data will be stored in a password-protected google drive with restricted access and on an external, password protected hard drive that is then stored in a locked cabinet. This means that only the researcher will have access to your data, and possibly her supervisor as well in extraordinary circumstances. Transcripts of the data will be included in the final thesis, but these will be anonymised. The data will be stored for a minimum of ten years.

Data collection will be done in compliance with article 8 in the Charter of Fundamental Rights of the European Union. In addition to the EU charter, the collection of data will be done in compliance with the data protection acts, legislation, and directives of the University of York. You have the right to access your data at any time by contacting Ashley. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project.

All efforts will be made to anonymise your data if you choose. You may be assigned a pseudonym by Ashley or appoint one to yourself – please see the consent page for more information. Due to the nature of the research and of disabilities themselves, it cannot be guaranteed that all data will remain completely anonymous, but every effort will be taken to keep your identity confidential.

## 5. Will I see the results of my data?

Yes! The final thesis will be published and deposited in an open-access repository. Additionally, if you would like copies of sections that pertain to your data, please tick the appropriate box on the consent form and they will be sent to you when the time comes.

## 6. Further Information and Contacts.

Taking part in this research gives you the opportunity to contribute to an original piece of research and to have your opinions and experiences heard. We hope that taking part will be an interesting and enjoyable experience for you. However, in the unlikely event that participating in this study causes you any form of emotional distress, please contact Ashley or one of the other people below.
- Ashley Fisher (researcher): af956@york.ac.uk
- Dr Keith Allen (Chair of the Arts and Humanities Ethics Committee): keith.allen@york.ac.uk
- Durham Burt (Data Protection officer): dataprotection@york.ac.uk
- Dr James Taylor (Archaeology Department Ethics Representative): james.s.taylor@york.ac.uk

This research has been approved by the Arts & Humanities Ethics Committee of the University of York.

# Out of Sight, Out of Mind: Accessibility for Hidden Disabilities in Museums and Heritage Sites (Pilot Study)

# Consent Form.

Participant name:

Participant signature:

Participant email address:

Date:

Please read below and tick each of the boxes to show your agreement with each statement:

- I have read and understood the project Information Sheet and have had the opportunity to ask questions about the research.

- I understand that my participation in this study is voluntary and I may leave the study at any time without penalty and without giving a reason.

- I consent to any interviews I participate in being recorded.

- I understand that all information I give will be stored in the data storage systems of the University of York, in line with University data management policies.

- I agree for my data to be used under condition of anonymity. I understand that my identity will be altered/obscured in photo, video and other visual and audio records.

- I wish to be identified as: _____. (**required if you wish to remain anonymous**)

# Appendix C – Transcripts.

This appendix contains all the transcripts that were created throughout the course of data collection. They are arranged alphabetically by participant's name – except Teagan and Kasi, who are listed together.

## 1. Aaron.

Aaron is a man with autism, bipolar disorder, and OCD.

### 1.1. Pre-visit Interview.

I met Aaron at a café in York to conduct this interview on 28 November, 2019.

Ashley Fisher
Alright, so I'm Ashley, we've emailed a few times. And before we get started, I just wanted to go over a few things to make sure we're on the same page. My research is looking at accessibility for people with hidden disabilities in museums and heritage sites. And you've been asked to be a participant because you have a hidden disability. So as I mentioned, we'll have three different meetings one now, so I can learn how you prepare for a trip. One immediately after this where we go to the museum – in your case treasurer's house – I have a basic outline for things we'll do. But by and large, I want you to leave the visit, so I can understand how your disability might impact your visit, then after the museum visit will go to café or something and have a chat about the experience as a whole. And then a couple days from now, we'll meet up again and have a chat again about that museum and other museums. That make sense.

Aaron
Yeah.

Ashley Fisher
Wonderful. So I've got a copy of the information sheet as well as the consent form. So if you want to have a look at that, and then sign. Yes, excellent. Thank you very much. So you have, As we discuss, OCD, Asperger's, bipolar and insomnia, right. All right, I've done research on them. And I have OCD myself, but I want to hear how you define these conditions and how they interact on your daily life.

Aaron
Okay, I think the best way to define OCD is we often hear a lot of people say, oh, I've got OCD about the worst possible thing to anyone who actually has OCD you can say. So part of defining OCD is anxiety. So like Monica on Friends, she enjoys cleaning.

Ashley Fisher
Yes. So yeah,

Aaron
it's when you don't enjoy. So like, most my life, the OCD was just for manifestations. So usually, for most people OCD is a certain thing, but OCD usually hits around 12, 13. I had it when I was like 4. Dad who was a sergeant in the army so he didn't really understand it. so it

344

was like cleaning quarantine kind of stuff, which evolved to doing things in four, so there were four members of my family. So you get up four times in the morning and go back to sleep, which is impossible. To eat four meals et cetera. And then OCD is chronic, you know, it kind of goes into pure love, which is what killed Joey Ramone and how he was I think was the richest guy in the world at the time. Yeah, the richest guy in the world was killed by... but yeah. So like now it's intrusive thoughts. So it's kind of like the worst thing that you can imagine going through your mind. So the only kind of way to solve it is by not giving fuck. you like rather than swimming against the tide, just let it take you away. So, if you kind of... it is a horrible for the premise of your mind you imagine your Mum dying or something horrible if you kind of have some like magnetism to that thought it gets worse. So you have to kind of say maybe, Yeah, fuck it might happen might not and then the thought just dies away. So, the consequence can be kind of reckless behaviour. But, you know, it's better than constant rumination. Yeah. In terms of bipolar, so I have like rapid cycling. Okay, so sporadic entirely, so it's not the typical 12 weeks of depression, 12 weeks mania. It's could be half a day of madness, half a day of fine. and there's no routine or prediction. So that makes life kind of impossible. But you know 24 seven so far so yeah. And I guess both of those cause depression. My depression is a consequence not the chemical... brain chemistry.

Ashley Fisher
Yeah.

Aaron
Some people just get depression. I think they cause depression and some of it is caused from PTSD So.. I think it is but I don't know. But like, I'm still high functioning. I read like five books this morning. I read a book five times, but it's one of my favourite books, I read it like... started at 4am, finished at like six?

Ashley Fisher
Yeah.

Aaron
I remember it was like the 19th time I read that book. When I was so when we came back from Cyprus, we had a staying tenant in one of my dad's- well, our house that we lived in before in Cyprus. Yeah, so I'm like an army brat. And we went to video my brother who happens to be a marine. He was not there. It was not like this day. I was, I went with my mom and dad, to video this piece of shit. Like he wouldn't leave our house, he ran out and hit my mom with a hammer and she was in a coma for four months. I wouldn't give a statement. I was doing nothing. Yeah. So I think like consciously every day, I don't think about it. Maybe I'm gonna make jokes like on Shark Week, we make jokes when we see a hammerhead shark to chase around with like a hammer. So like we use humour. I think subconsciously like, yeah, I guess I have it.

Ashley Fisher
I definitely got [understand] it. How do you think the bipolar and the OCD interact? Hard to get routines?

Aaron
Yeah. I think this is... the thing with OCD is it's... I used to have really bad social anxiety. I think it's because of the OCD. Because people notice when you know, like, when I was younger, they obviously notice the physical kind of tapping, they can now notice the mental. like that someone can see when you're ruminating You know, when you're in lecture

someone can see when your thoughts are just rolling over. And in essays I read so much poetry that I like to have an obsession with writing in like, iambic pentameter so like that's not how you write an archaeology essay. It might be nice to read you know, like, you know Lord Byron didn't study archaeology so it's usually like the technique I do is I write it like that, gonna help it and then I kind of meditate with this mantra in a cold shower and then just kind of edit and then remotely and I read it like 15 times, delete it all and then write out again.

Ashley Fisher
Okay

Aaron
so this seems to work but it's taking a lot of effort. I've got a degree in classics already So, okay, yeah. So like, yeah. But it depends what it will be like so for example OCD. I've done a lot of research into biochemistry. So everyone, there was a study in 1962. I think most people who suffer from OCD every OCD has a lack of GABA. So there's a few GABA agonist medicines. benzodiazepines. So if I had a shot of whiskey, I can write an essay. Okay, so I'm not drunk. Yeah, it just kind of little. Yeah. So well that would do would allow me to have the same GABA that everyone else has. Yeah, no, yeah, yeah. So things that that help. Also cold showers increase GABA, exercises increases GABA, Meditation mantra. Yeah. I don't know how to deal with it. It's like kind of being born blind. I don't know any different.

Ashley Fisher
Now what about the Asperger's

Aaron
Yeah, so I'm like it's in my medical record, but certainly medical conditions that so many similarities and symptoms that it can be like misdiagnosed? Yeah, obviously with Asperger's, it's usually the kind of defining characteristic of someone having Asperger's is the inability to pick up nonverbal communication but I don't know it seems that when I'm on a high, I'm fine. Yeah, so I think there might be a misdiagnosis.  Okay. But like I'm not a huge fan of people really, in the hands of the people so like when I used to live in London for example, which was hell, I used to make sure that I went to like natural history museum on like a bank holiday, because ironic, on a bank holiday, you'd expect [lots of people] Yeah, but they weren't that they were all kind of doing things with their families. There were no tourists, and it was actually more empty on the bank holiday than it was at any other time of the year So I just used to go on bank holiday. I enjoy Halloween because I can wear a mask. Yeah.

Ashley Fisher
So going off the bank holiday thing, what do you do when you are preparing to go to a museum? What kind of what kind of things do you look at? Or do you just go?

Aaron
Um, so I guess like if it was like a particular museum that was so when I went to all the Smithsonian in DC, like they would be an insane not to go. Yeah, like even though his background, the English facet of the Lord do so better that he gave all of his wealth to an American developer to build one of the greatest museums in the world. So I think sometimes when the passion to go there is stronger than the anxiety, then you just say fuck it. And plus the Native American Museum, the Smithsonian Native American, they had great food. Before I went with my Dad and it was fun. So if my Dad with me or my lady friend in DC, then it's fine. on my own, not so much. Okay. So if I go alone, I usually I have plan before I

went or I kind of just instead of like most museums are done, you know chronologically and for the time like Native American especially. So if there are a lot of people, I couldn't follow the chronological order, I'd have to go backwards. Okay. So, yeah, but yeah, these museums are so great that my interest in this subject is overpowering.

Ashley Fisher
do you check out any other websites or anything like that before you go to a place?

Aaron
Yeah, yeah.

Ashley Fisher
What sort of things Do you look at other websites?

Aaron
I just look for posterity. Yeah. Like there's not like there's not really like a mental disabled ramp? Yeah. They don't really say, you know, yeah, there's a metaphysical realm that you can take into this museum. So, yeah, there's no.

Ashley Fisher
So you wouldn't look at like, an accessibility guide or their access page.

Aaron
Oh, no, I guess I wouldn't, because I wouldn't expect that to be anything.

Ashley Fisher
Sure.

Aaron
There may be something in some of the museums in DC about mental health access, but I don't think there is. Yeah, there is. Yeah.

Ashley Fisher
All right. Do you bring anything with you as like a comfort object or soothing thing or so

Aaron
yeah, so sounds kind of fun. Far out. So I read Lord of the Rings every autumn and Gandalf's advice. This was quite is the you know, smoking a pipe is like quite meditative. I stay with the Hare Krishna every year and they all smoke pipes, tobacco obviously, and the thing about Pipe is we don't take it back into your lungs. You might get mouth cancer, but you won't get lung cancer. But it takes around about an hour just to pack it perfectly. Like if it's not packed perfectly, it won't smoke perfectly. Yes. So you spend an hour just packing the pipe type of thing. and then you have to get a match like you can lay it with a zippo or you can light it but it's not really like anything else. And then you have to be conscious of not taking it back into your lungs. So the whole experience is very in the moment very present, so I bring a pipe with me everywhere. Okay, so like that Sometimes even if I'm not smoking it, I just have it in my mouth yet and he brings in like Kassala and yeah, I guess this is all

Ashley Fisher
excellent. Um, do you prepare for any potential scenarios or anything that would happen on a trip?

Aaron
No, no. Like, there's the Doom is always impending.

Ashley Fisher
So yeah.

Aaron
I've had one thing and something else pops up so much fun. I can't face all of my back or anything. So yeah.

Ashley Fisher
Alright, and would you say it takes you an average amount of time to get ready?

Aaron
Actually, it is quite long. I'm usually kind of like when I wake up it's like glass, a glass touching every morning. It's not really it's not like a shock anymore. It's just, you know. So like, it takes me time to adjust to that, read meditations by Marcus Aurelius, used to read the whole book in the morning but I don't have enough time anymore. So yeah, usually just read one of the chapters of the book. Like I read Book Three today. They're very sporadic. Yes, what happens usually in the morning, and then I have like a 10 minute Cold Shower until I'm blue. Then I meditate like five or 10 minutes and then dress, go and have a cigarette, come back. Call my mom. And then I'll be ready. Okay, so I usually wake up about I don't sleep. So. Yeah. If I have like a lecture at say 10, I start preparing oh six. Okay.

Ashley Fisher
It sounds like a lot of it is sort of mental preparation to get ready for different things.

Aaron
Mhm.

Ashley Fisher
Excellent. So that's all the questions I have for right now. We'll head over to Treasurer's house from here. We're going to be doing what's called a semi structured visit, which basically means you are going to take the lead. There's going to be a few specific things that we make sure that we do. One is visiting a particular room for treasures house. It's the blue drawing room and I'll let you know when we get there. We'll also have you talk to a staff member for help or just listen to them, whatever you're comfortable with purchasing a small item from the shop I've got five pounds, knock yourself out there, and then visiting the toilets. So pretty simple, common, everyday things that most people do on a visit. And then after the visit will go to a café or something and have a little bit of a debrief. We'll go through a visit audit just to just kind of a checklist to see how do you think the museum did in certain areas and then also have a chat about the rest of the visit and make sense? Yeah, perfect. Excellent. All right. Let me

## 1.2. Site Visit.

Our visit to Treasurer's House took place on the same day. The audio was recorded, but there was nothing relevant to transcribe.

## 1.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
How easy was it to find museum from the street?

Aaron
Well, you've got me so I still have an American SIM so I don't have GPS So yeah would upon that right So that's a bit of a record. I didn't know what the proposal was. I was just looking up so you know, I wouldn't I wouldn't have found that there was no I wasn't really looking out for him. So I didn't need to connect with it. So yeah.

Ashley Fisher
All right. Let's find the and was the layout of the museum You

Aaron
know, it was just it was just like, you know, some guy making up for lack of points in yesterday, so he was just an egomaniac I think. So everybody is here as such, like it was no, it wasn't like, you know, highly intelligent guy was no drastic, drastic. in chronological order. Yesterday was just this house. So the layout is just this How about the hospital

Ashley Fisher
for sporadic thinking about shop specifically was there enough space to move around shop

Aaron
Well, I guess if you don't want to buy anything on those things you're fine

Ashley Fisher
[would you have found the shop]

Aaron
I think I've seen this I think I would have found it Yeah. I just hate you always have to go through the shop quite a toilets. Capitalism twice when I was I guess it was easy to find

Ashley Fisher
Were the toilets easy to find

Aaron
Yeah.

Ashley Fisher

Were they clean

Aaron
but the use of this delusion to the automatic war comes up just never happens to exist doing and then some guy comes up to me and do the same thing and then laughing more comes up so and also the world since we're in have the same distance between polite people because we both know that you know they were free They're not they had total role in those college students

Ashley Fisher
Thinking about the staff now. Was the staff member able to answer your question?

Aaron
Oh, yeah, I think I seen David speaking. Yeah. And they were warm, welcoming. You know, they weren't stand for that. But anyway, I took one. Sounds good. It's kind of like, you know that, you know, the Clifford smiled of that. Yeah. I went, that's my friend and girl who was working on that. I was asking her questions. I'll see the 19 Taurus came over. But I was being directed. So asked me for questions. It was just to say, Great job. Wasn't a challenge. She was a little more sun in the rain. Oh, that was I'd love to speak to people about this right it's cold and rain. So I think maybe we'll have the brother the guy was kind of funny as well. He was ...especially for an old guy he was strange the other way kind of appreciated that special for by Sir I think he was pretty supportive thing if you're going to be a more of that money so I liked him he was a woman. First one is new to so yeah, she knew that she didn't know, which means So like seven like why are so and really relevant to the museum three owners. So she gave

Ashley Fisher
me the best answer.

Aaron
Yeah. I'm just meticulous.

Ashley Fisher
Do you feel welcome?

Aaron
Yeah, I think I did. Yeah. Like I went with you so it was different hello yeah, I think it was definitely like not recently here in London where people just walk around difficult darkness or other mainly in 40 facilitators anyone can get another so yeah, yeah whatever they like funny because if this was like 10 years ago out of my social gatherings so, I think depending on you know like kind of hygiene said stage uncle and now

Ashley Fisher
[noise levels]

Aaron
Pretty good I think the kind of guides for loud enough that you could hear without having to be an active participant in here. So you go return the living God people advertise every

made saying that the conversation ends this most announced like a person speaking for recorded voice share

Ashley Fisher
[do you prefer interacting with live people or listening to the recording]

Aaron
that Andrea luck with that and you know you don't have to react And you know you kind of get the feeling if there's a tour guide or whatever in there, you know how many times as he said the same thing, you know, he must say it, you know, he must have to put on a happy face, working on those jokes once again. So I think There's no pressure [with the recording] suppose it's just the voice is not like you know – as long as it's an actual voice and not a  voice generated by a computer

Ashley Fisher
how's the lighting

Aaron
but the room is didn't know it wasn't consistent. Some were really dark and some were really light, like some museums in DC I like- it's quite dark but when you get to love the actual exhibition or  the text, it's illuminated so you can read the text and the things – so they light up what matters, what doesn't matter is more Ambient

Ashley Fisher
so like spotlights you could read. places that were too light to dark just

Aaron
toilet was a bit light only have one beautiful life

Ashley Fisher
Thinking about the blue drawing room specifically, how was the noise level in there

Aaron
Nothing that really bothered me

Ashley Fisher
and lighting

Aaron
nothing wrong with a string guy was

Ashley Fisher
enough places to sit or rest

Aaron
no

Ashley Fisher
What's your What's your favourite thing about

Aaron
the tapestries

Ashley Fisher
least favourite thing

Aaron
trying to find it

Ashley Fisher
So what's one good thing related to accessibility

Aaron
I don't think … Sorry, but it wasn't busy they pretty much it was but it wasn't.

Ashley Fisher
So less crowded. [something they can improve on]

Aaron
Below the show there was no history but there's no progress. So like you have to speak to someone if you want to know the history [???] So I want to speak to whoever asked about what enough You know, I think maybe if they had more information about the paintings  because they were

Ashley Fisher
you feel like you're treated any differently than any of the other?

Aaron
I think the staff for good is like sometimes we go to shop like a clothing shop, instantly get just tap on the cloud. They seem to pick up if you wanted, if you want help or not. Some guides, they didn't speak to you because they knew you didn't need...Same thing, others knew if you wanted appreciate yeah

Ashley Fisher
If your disability had been visible, do you think you would have been treated differently

Aaron
Yeah. look in their eyes hair standing up on their arms people kinda taking steps back condescending, patronising

Ashley Fisher
Would you visit again?

Aaron

If I had a friend I guess so the only know that I would like personally I didn't enjoy it, but I mean that wasn't the museums' fault, it's not about museum says no never go about that no

Ashley Fisher

If you could tell the museum one thing regarding the accessibility of their site, what would it be?

Aaron

I think there's more [talking about bipolar] rapid cycle so I Think sometimes
they should have maybe days whether a person every single room to tell you about everything like maybe just have enough information in text on the walls, [basically, less pressure to interact socially to get information]

## 1.4. Follow-up Interview.

I was unable to conduct a follow-up interview with Aaron as he stopped answering my emails and I had no other means of contacting him.

# 2. Alfie.

Alfie is a man with dyslexia and monocular vision.

## 2.1. Pre-visit Interview.

I met Alfie at a café to conduct this interview on 21 January 2020.

Ashley Fisher

No, it's just if someone wants to go by a different name. Excellent. Thank you very much. Now that's going into cabinets in case anyone wants to see it. So, my name is Ashley, we've emailed a few times. Okay, so I have a few questions for you about your disability. You said that you had dyslexia and low vision or visual difficulties – can you tell me more about that?

Alfie

Sure. So I find that my dyslexia, it takes me a long time to read anything, so often I'm locked out to reading stuff – like the form, like, yeah, I could read it, but... but my main problem is like my sight. So I see out of one eye. Okay. So everything is 2D.

Ashley Fisher
Right.

Alfie

So that means that getting around is quite fun. Sometimes crossing a road from the other side. Yeah.

Ashley Fisher

That's going to be complicated. Yeah.

Alfie

Yeah. At least exciting times.

Ashley Fisher
I can imagine. And those are both conditions that you've been born. Is that correct? Yeah. Okay. So it's not like your vision has declined over time. It's just, this is what you're used to.

Alfie
So the vision has declined. Okay. It's been... I've only been able to see out of one eye as long as I can remember. Okay. Yeah. But yeah, the vision's still getting worse. So it's getting more exciting.

Ashley Fisher
Very exciting. Was it more of a natural bad eyes, run in your family, and just That's how it is or is it something

Alfie
It's in my family, but I am the worst in the family and also they – the rest of them who've got binocular vision.

Ashley Fisher
Yeah because you've got monocular vision. All right. Now obviously that has an impact on reading Do you find it has a different impact on reading on printed material versus digital material?

Alfie
Not that much.

Ashley Fisher
 Okay.

Alfie
I guess I'm more used to readings on laptops nowadays. Okay, it doesn't strain my eyes to read it easier. Yeah. Online, I find that my eyes will skip lines. Whereas on paper. I'm very careful. It takes a lot longer.

Ashley Fisher
Yeah. Okay. Excellent. So let's talk about your preparation for going to museums. And what kind of research Do you do before you go to a place?

Alfie
So before I will go to a place I would often see what was there to see what facilities they had. Okay. See if they have a café.

Ashley Fisher
sure.

Alfie

So try and work out if there's any particular exhibit. So just a general background,

Ashley Fisher
basic things like that. Yeah. Cost, hours. Where do you check to find that information? online?

Alfie
online.

Ashley Fisher
Okay. Is it on their website? Is it on TripAdvisor?

Alfie
It's either on Google or on their website, okay. spending it.

Ashley Fisher
Yeah. Have you looked at the barley Hall website at all? Totally fine if you haven't.

Alfie
I think I have.

Ashley Fisher
Okay.

Alfie
Like a year ago.

Ashley Fisher
Fair enough.

Alfie
Yeah. You're welcome for that honesty.

Ashley Fisher
This is what we like. Um, are there any particular accessibility tools that you use like a screen reader or a colour overlay or anything like that? Oh, excellent.

Alfie
Often I make the text bigger. So I magnify Okay, but not using that access tool, just zoom in.

Ashley Fisher
zoom in?

Alfie
Yeah.

Ashley Fisher
Excellent. Um, do you bring anything with you when you go somewhere?

Alfie
As in like wallets and coat

Ashley Fisher
Anything. Okay?

Alfie
Often I would bring a friend Okay. And also my wallet and phone. Yeah, so if I don't have enough time to read all the information, I can take a photo of it. Okay. And then if I'm interested later I can read it. Yeah.

Ashley Fisher
And you normally take a friend is that just because you prefer going around a museum with someone else or Okay, yeah, yeah,

Alfie
They help motivate me to go to a museum and also depending on who I'm with, I can ask them a question about [things]. I can see from here, but I can't quite tell exactly what it is.

Ashley Fisher
Yeah, sure.

Alfie
Well, I can ask them to just summarize a portion of it says in the text. Yeah. Yeah.

Ashley Fisher
So it's sort of like a, a, an unofficial companion kind of thing. Yeah.

Alfie
Yeah.

Ashley Fisher
Do you plan for any emergencies or eventualities?

Alfie
Nope

Ashley Fisher
It sounds like there isn't necessarily any emergencies or situations that might spring up because of your disability. So

Alfie
if my glasses broke, I would just carry on walking and just hope for the best

Ashley Fisher
Yeah, yeah, I know that- I don't have quite as bad vision as you but I have negative 7.5 so like, it's pretty bad. Yeah. I super get that.

Alfie
You have similar vision to what I have. Yeah.

Ashley Fisher
Yeah, it's not quite fun. So for the visit itself will go in just a few minutes. We're calling it a semi structured visit. By and large you're leading it so it can last five minutes if you just want it to last five minutes can last for until they close if you want up to you. We'll go around, visit like you normally would. There's just a couple basic things that I'm going to make sure that we hit so visiting a particular exhibition, barley Hall, it's gonna be the parlour, which is upstairs asking a staff member for help, purchasing a small item from the shop by five pounds cash, so don't worry about that. And visiting. I know we're spending big on this one. Oh, and visiting the toilets. So very normal things that everybody does. I'm going to have a microphone on you for the visit if that's okay. Yeah. But it just helps me have specific points of comparison between all the participants, and then afterwards, we'll go maybe back here. If it's still open. I have no idea what the refectory does anymore. And just have a quick debrief and go through visit audit worksheet and does that sound okay?

## 2.2. Site Visit.

Our visit to Barley Hall took place on the same day.

Alfie
Hopefully you can hear me.

Ashley Fisher
We'll find out. Alright, can you stick that in your pocket...

Unknown Speaker
[note: video in steward's room is VERY loud and covering up a lot Ashley and Alfie's speech until they leave the area]

Ashley Fisher
[in the Great Hall] Can you read the sign.

Alfie
I just... like... can we pick them up?

Ashley Fisher
Yes, yes, they are can be picked up the font that.... it's not dyslexia friendly I can tell you that right now.

Alfie
Are you dyslexic?

Ashley Fisher
I'm not but I've done a looooot of research on dyslexia friendly fonts how is the colour contrast color

Alfie
It's actually okay

Ashley Fisher
some people find light text on a dark background hard Like place.. the brightness of the area will impact how readable something is.

Alfie
Yes [discussing text panels hanging on the wall] Better than the ones downstairs which are a lot smaller.

Ashley Fisher
So these are newer ones. Yeah. Just barely a year while the others are over four or five years. Yes, magic and mystery. It's about mystical beliefs and how it sort of science for medieval people. Okay. It's like the magic and  science where the same.  especially medicine and things like that. So,

Alfie
yeah. Until people start being better.

Ashley Fisher
We don't talk about that.

Alfie
This herb helps in the fighting against weasels and dragons! For some reason this is actually quite easy to read.

Ashley Fisher
Interesting. These are pretty much the same... text wise...

Alfie
Maybe it's the lighting then? Maybe it's the balance of less text.

Ashley Fisher
I was wondering maybe had to do with the spacing around the text

Alfie
maybe As in from line to line and rest of it.

Ashley Fisher

Yeah. Yeah. Like this looks a lot more crowded with this. It looks a lot more spread out or wider

Alfie
[talking about how one particular sign is difficult to read]

Ashley Fisher
yeah, that has much more good background at the bottom. Yeah

Alfie
I could read the one that had the biggest text but I couldn't really read the others. [Alfie enjoys making a wand] Yeah, basically the same

Ashley Fisher
would more space in between. So it was closer to this spacing...

Alfie
Often when I'm reading this one, I'll often think of that line for so re-read second yes

Ashley Fisher
What do you think of the lighting in this room? [lesser chamber]

Alfie
It's very hard to read anything. I can stand here and keep reading it, but I'll enjoy things and the place less.

Ashley Fisher
Okay. So it's better use of your energy to go Okay, that's an astrolabe, that's a _____ and that's all you need to know.

Alfie
Yeah. It just means I know things are, really [but not much else] [went through and read what the different dream interpretations were on a board]

Ashley Fisher
Or like that first letter [in the fancy font], and then like a more.. easier to read font for the rest of it.

Alfie
Yeah

Ashley Fisher
They can have their artistic thing, But then also people can read it

Alfie

Yeah. And again, too much text It's harder to read in here [the study – because of the lighting]. In a dark room, there's also less contrast

Ashley Fisher
so it's not a big deal that it's quite this dark but can you see anything? So

Alfie
I can see what things are, I can't tell where they are. It doesn't matter so much, the detail.

## 2.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
Okay, so we just came back from barley hall and we walked to the site, how well or poorly were things signposted to get there do you think? Did you notice any signs directing you there?

Alfie
I didn't. Okay. Until the alleyway.

Ashley Fisher
Okay, so I think that's coffee yard. Yeah, okay

Alfie
yeah I didn't notice them. They may have been there

Ashley Fisher
I genuinely don't know so okay. excellent How easy was it to get there from King's manor to get to there?

Alfie
Quite easy

Ashley Fisher
quite easy okay yeah

Alfie
building work doesn't help but that's just a temporary issue

Ashley Fisher
yeah. it is York and it is construction season so

Alfie
yeah I didn't really know where the entrance was. when we're putting on the mic I just thought that was around the corner from the entrance

Ashley Fisher
Was it easy to find the museum from the street. silly question for Barley Hall but

Alfie
From the street with the building work [Stonegate]?

Ashley Fisher
Yeah.

Alfie
Yeah was okay. I couldn't find the entrance but finding Barley Hall itself was not difficult

Ashley Fisher
Did you understand the layout of the museum?

Alfie
It was a bit of an odd layout, but I knew where to walk. Okay. I would have missed that one section [from the study to the other side]. Yeah.

Ashley Fisher
Thinking about the shop. How is the signage in there

Alfie
As in for...?

Ashley Fisher
as in the shop or the ticket signs, okay. Great signs.

Alfie
Yeah, pretty small okay. Yeah. I decided just to ignore them and look at the items themselves. Okay. I think the item I got in the end didn't even have a label.

Ashley Fisher
And was there enough space to move around the shop?

Alfie
Yeah.

Ashley Fisher
And could you navigate around the shop easily or?

Alfie
Yeah. I don't know how it would be if someone was less mobile, but for me it was fine.

Ashley Fisher
Okay. Could you find the toilets?

Alfie
Yes.

Ashley Fisher
Was it clean?

Alfie
Yes,

Ashley Fisher
Was the toilet floor clean.

Alfie
I think so.

Ashley Fisher
We're gonna go yes.

Alfie
I only looked down when I stepped in the little hole thing.

Ashley Fisher
Alright, so the staff was the team member able to, you know, answer your question to your satisfaction.

Alfie
It was a good answer. Not what I expected, which is always good.

Ashley Fisher
Yeah. Did you feel welcomed in the museum?

Alfie
Yeah, yeah.

Ashley Fisher
Okay, thinking about the exhibits now, how were the displays just in general,

Alfie
They weren't bad – it was nice that they were interactive. You could get a better understanding of it. I'm someone who does things better by touch than reading. So

Ashley Fisher
Could you read the fonts?

Alfie
Not everywhere, not everywhere.


Ashley Fisher
And that was partly because of the font itself and the size and the lighting and spacing of just


Alfie
And the background and material.


Ashley Fisher
Yeah, yeah. How was the colour contrast?


Alfie
Some places were fine, some places were not. Like when it had a background it was difficult to read and then yeah, I'm also depending on the lighting in the room, if the lighting was dark. Yeah.


Ashley Fisher
All right. How was the volume on the videos


Alfie
in the main when you entered there are quite hard to hear because people where being quite noisy elsewhere. Oh, yeah. The one upstairs about dreams was fine.


Ashley Fisher
Could you understand the stories and tales that the museum told


Alfie
I understood the part about the witches upstairs. Okay. I didn't really get that many narratives. Okay.


Ashley Fisher
Okay. That was the overall noise level of the place


Alfie
Fine. It had good noise cancelling. Considering the [building] work.


Ashley Fisher
We're any places too loud?


Alfie
No, no. Other than the street.


Ashley Fisher
Yeah. Were any places too quiet?

Alfie
No. Okay.

Ashley Fisher
Are you the type of person that says no place in the museum is too quiet or the type of person that says no places too loud in a museum?

Alfie
Doesn't really matter. Okay. I don't know. I think somewhere could get too noisy for me. I just wouldn't be able to see.

Ashley Fisher
Yeah, sure. How was the overall lighting?

Alfie
Not bad. Okay. Well, in parts, it wasn't bad. Yeah. In parts it was really bad.

Unknown Speaker
All right. So what were some of the parts? Well, were there any parts that were too light or bright

Alfie
I found upstairs, there was one room [the parlour] where it was hard to read the label because the light was shining on it. Yeah, yeah.

Ashley Fisher
But that was more because of the glare on the thing.

Alfie
Yeah, yeah.

Ashley Fisher
And were some places to dark.

Alfie
Yes. Yes.

Ashley Fisher
Okay. What kind of places?

Alfie
The food places.

Ashley Fisher
Yeah, the pantry and the butlery.

Alfie
That's the one. Upstairs that was the room we went off to first

Ashley Fisher
the lesser chamber or the greater chamber?

Alfie
The... lesser one?

Ashley Fisher
the dream one.

Alfie
Yeah. That was very dark. I think in the other rooms, they were light in parts and dark in parts. Yeah. But those rooms in particular...

Ashley Fisher
Those rooms were particularly bad Okay, were there enough places to sit and or rest?

Alfie
I don't know? I didn't look for any. I'm someone who would just sit on a  doorstep. Okay.

Ashley Fisher
So having a nearby place it isn't necessarily a priority. Thinking about the parlour so the room that all smelly things and where you did the wand? Yeah. How were the displays in that room?

Alfie
They were better.

Ashley Fisher
Yeah. What made them better?

Alfie
They were bigger, more space, better lighting in the room in general. Yeah. Material of the boards wasn't bad. They didn't have background graphics. And then next to the gemstones, that was quite small and immoveable one.

Ashley Fisher
Sure. So having the movable boards really, really helps.

Alfie
Yeah.

Ashley Fisher

And could you read the fonts in there in those ones?

Alfie
I could. They were better than the rest. Yeah. But it was the same font as everywhere else.

Ashley Fisher
Yeah. Yeah, I'm pretty sure they use the same font throughout but it feels different in certain places somehow. What about the colour contrast?

Alfie
Not bad

Ashley Fisher
Could you understand the stories and tales told in that room?

Alfie
Yeah,.

Ashley Fisher
Yeah, cuz that was the witches

Alfie
Yeah, that was the one I did get.

Ashley Fisher
How was the noise level in that area?

Alfie
Not bad.

Ashley Fisher
How was the lighting in that area?

Alfie
Good, good.

Ashley Fisher
And were there places enough places to sit and or rest there?

Alfie
Didn't notice.

Ashley Fisher
Okay. That's fine. Alright, so that is our visit audit.

Alfie
Amazing

Ashley Fisher
Now I got a couple other questions if that's okay.

Alfie
Sure.

Ashley Fisher
What was your favourite thing about the museum in general?

Alfie
I thought it was interactive. Okay. Not many museums are.

Ashley Fisher
What was your least favourite thing about the museum in general?

Alfie
Probably the boards.

Ashley Fisher
Just how frustrating it was that you couldn't always read it? Okay,

Alfie
yes. How when I stood reading it how draining It was

Ashley Fisher
okay. What was one good thing related to accessibility or disability museum?

Alfie
That's a good question. Probably quite a few.

Ashley Fisher
You can say as many things as you like, but at least one would be nice. Yeah.

Alfie
The sound was relatively good, okay.

Ashley Fisher
Like in terms of volume level or in terms of how it's not very echo in there.

Alfie
Both.

Ashley Fisher
 Okay.

Alfie
Also I didn't see anything that would affect colour blindness.

Ashley Fisher
Okay, yep.

Alfie
Once again it was interactive, it was more involved.

Ashley Fisher
yeah. certainly have more senses involved in it that way

Alfie
Yeah. So if you, if you can't use one you had other one which would help. Yeah.

Ashley Fisher
Alright, so what's one bad thing about accessibility?

Alfie
The boards were hard to read. Also if you were less mobile, it would be very hard, and the steps leaning odd ways

Ashley Fisher
Do you think they need to replace the steps or put a sign there or inform people

Alfie
I think informing might be good. Once you saw the 'beware step' in the way [it was easy to recognise them further on].

Ashley Fisher
Yeah, okay. Yeah. Sure. Right. Um, did any barriers jumped out at you

Alfie
The steps. And that there's just many steps in general. Yeah.

Ashley Fisher
Do you think the museum could provide anything that would be helpful for you to go around?

Alfie
For me personally? An audio thing. Then I wouldn't be so reliant trying to read everything. Yeah.

Ashley Fisher
Could the museum design anything into their exhibitions from the very beginning that would help? Like the font choice, for example,

Alfie
the boards could be better. Yeah. And not just for the font but making sure it's a consistent size that is big enough to be read. Sure. On a material that doesn't reflect. Even in the rooms where there's low light, if you get the basics sorted out, it will be okay.

Ashley Fisher
Yeah, okay. Yeah. How did the staff make you feel?

Alfie
They were friendly, so welcomed? I guess.

Ashley Fisher
There's not a lot of stuff interaction in that museum. Do you think that's a good thing or bad thing? Just the thing. Okay,

Alfie
Just a thing. sometimes it's useful, sometimes you just get stuck somewhere.

Ashley Fisher
Yeah. Okay. Do you think you would have been treated differently if your disability was visible?

Alfie
Don't think do.

Ashley Fisher
Okay. Is that good or a bad thing? Or again, just a thing?

Alfie
Just a thing. Yeah. So there's good because they were just so friendly. I don't think they would have caused me hassle with more visible. but also

Ashley Fisher
Yeah, so that was a good base level friendliness that would cover just everybody.

Alfie
Yeah.

Ashley Fisher
Would you visit the museum again?

Alfie

Probably.

Ashley Fisher
Why?

Alfie
It is an interesting place. Okay.

Ashley Fisher
If you could tell the museum one thing regarding the accessibility of their site, what would it be?

Alfie
Make it [accessible].

Ashley Fisher
All right. What specifically would you have them change?

Alfie
For me it would be sorting out the basic font stuff. So is it big enough, visible enough.

Ashley Fisher
Anything else that pretty much

Alfie
I supposed making it possible to navigate without having to step over things? But yeah, I would imagine that would be impossible.

Ashley Fisher
in in a magic world where anything is possible.

Alfie
Yeah, yeah. Make magic happen.

Ashley Fisher
Yeah. Come on, the magic and mystery exhibition. We can do it. Yeah.

Alfie
Maybe it phone app as well.

Ashley Fisher
Excellent. Those are all the questions that I have. So, if it's alright with you, we'll have one more meeting and do some follow up questions. So I can send you those questions as well.

## 2.4. Follow-up Interview.

We met at a café in York on 25 January, 2020 to conduct this interview.


Ashley Fisher
Alright, so how have you been


Alfie
I've been very well? How are you?


Ashley Fisher
Pretty good. Getting ready for a Viking Festival, which is always very nice stressy at work. Yeah, it'll be fine. So I'm just doing a quick recap of our visits and some follow up questions. There was a big difference for you between the movable and the stationary text boards. Was that right?


Alfie
Yeah.


Ashley Fisher
Yeah. So being able to pick them up was helpful for them.


Alfie
Yeah.


Ashley Fisher
Okay. And then the ones on the wall, just awkward and


Alfie
yeah, some of them are good. Some of them weren't.


Ashley Fisher
Yeah. Okay. But by and large, the ones that you could pick up.


Alfie
Were better.


Ashley Fisher
Yeah. Okay. Now, you really like that it was a sensory experience. got lots of the senses involved, right? Yeah. Do you think that would change, that your experience would change if there were costumed interpreters around.


Alfie
I think that's always fun.


Ashley Fisher

Yeah, okay.

Alfie
Not necessarily accurate but it's always fun.

Ashley Fisher
And you mentioned a phone app. What would you like a phone app to look like

Alfie
to look like?

Ashley Fisher
Or just to do.

Alfie
Yeah. I like it to maybe have less text than the boards, some more I can listen to or have the option to do both, depending what you like. What's more, many of those things weren't actually about the building, and the building was the most interesting thing in a way.

Ashley Fisher
right So you said you would probably visit again?

Alfie
Yeah.

Ashley Fisher
Would you still is that still okay all right. Did a barley Hall reminds you of any other museums that you visited in good or bad ways?

Alfie
Remind me of my home one?

Ashley Fisher
Yeah,

Alfie
In the middle of nowhere in Hertfordshire.

Ashley Fisher
What's it called?

Alfie
Ashwell museum.

Ashley Fisher
is what's that one's about?

Alfie
That one is more to the building style of it all, the main bit was actually house in the pop world. The place had an interactive feel, like your part of it more. Okay.

Ashley Fisher
Yeah, tell me more about that. About the museum.

Alfie
Ashwell museum. Yeah. So it's basically this community museum. Okay. And it's run entirely by volunteers. Most of them were getting on a little bit

Ashley Fisher
as they tend to

Alfie
do, and it's always just really friendly there, as well, but it's similar to Barley Hall.

Ashley Fisher
Yeah. Okay.

Alfie
It's all being revamped, so I don't know what it's like now.

Ashley Fisher
Excellent. Are there any stellar museum experiences that stand out in your memories that you've seen?

Alfie
 from Barley Hall?,

Ashley Fisher
 anywhere

Alfie
Oh, that's good question. There was one, but I doubt I'll be able to remember where it was

Ashley Fisher
that's okay. Can you tell me about it.

Alfie
Trying to remember other than the fact that it was great. Yeah. So many good ones in the past. Natural Museum, okay.

Ashley Fisher
What do you like about it?

**Alfie**

how big it is but also you getting the information that you need. Go and do as you wish. Okay. also fairly interactive if you go to the Dino center. Okay.

**Ashley Fisher**

Excellent. do you think there's a there are different expectations in paying versus non paying museums?

**Alfie**

I think there is, in a way Yeah.

**Ashley Fisher**

Do you want to explain

**Alfie**

in paying ones, you expects to be a little bit better standard, expect everything to be more accessible to everything but also in a way you expect to be slightly more simplistic, less information. More about just trying to bring people in while other than actually artefacts and stories and such. Okay. free ones it's all about a little information and you can talk to us to find out more information. Yeah, whereas in paid ones. It's more about come here, see this Yeah, yeah not really engaging with the material or the information at all.

**Ashley Fisher**

So bit of a pessimistic view on paying versus non paying.

**Alfie**

Yeah, yeah.

**Ashley Fisher**

 Okay interesting

**Alfie**

as a student I like things free

**Ashley Fisher**

understandably Yeah.

**Alfie**

I guess in paid ones expecting a little bit more spacious more open better facilities like better cabinets and stuff. Yeah. they actually have the money to invest in

**Ashley Fisher**

yeah

**Alfie**

I guess the people my mind in a free one or more friendly because that just like don't have to be Yeah they're volunteering mostly. Yeah. Yes. Then again, at Barley Hall, they were friendly, so yeah. That was a long answer for you. You're welcome

Ashley Fisher
Thanks. I mean, these are good. Alright, um, do you really have a bad day versus a good day? for your disability.

Alfie
Not really

Ashley Fisher
Is it pretty just constant

Alfie
I guess. on a bad day I feel more tired I have less energy to put into trying to read stuff. Okay.

Ashley Fisher
So if we had gone on a bad day,

Alfie
I would not be able to read anything

Ashley Fisher
fair enough.

Alfie
I guess it's more of a mental attitude to it

Ashley Fisher
Yeah. This is quite personal question. So it's okay if you want. You want a minute? Do you consider yourself disabled? There's no right or wrong answer. This isn't a gotcha thing. So

Alfie
in some ways, yes. In some ways No. Okay. I don't notice it on a day to day thing. Uh huh. So rarely have the days where it's worse than others.

Ashley Fisher
Yeah.

Alfie
I don't really notice it, personally.

Ashley Fisher
Okay.

Alfie
However, I think I do because it limits the sort of things I can do. If I compared myself to how I was say 10 years ago, things are completely different. Okay, I stopped doing cricket because I can't see the ball anymore

Ashley Fisher
It was really fun.

Alfie
I used to play rugby without contact lenses.

Ashley Fisher
Oh wow. So would you consider yourself a disabled person or person with a disability?

Alfie
Person with a disability

Ashley Fisher
There's a lot of a lot of discussion and disability studies as to whether it should be person first or not. And right now, the leading consensus is it should be disabled person, but I feel like that's very exclusive of people with hidden disabilities.

Alfie
Okay,

Ashley Fisher
because every single person so far that I've asked, they've said person with a disability And I find that really, really interesting. So, yeah. Do you have any questions for me? Cuz that's all my questions. So

Alfie
not really

Ashley Fisher
okay, that's fine. If you do, please email me, if you remember that place. So yeah, thank you for being part of this research.

Alfie
I thought of one [cool museum experience]. Yes, it was in the Barbican in London, okay. And it was all about tech all about the ways in which technology has been built up. So it's less more about artifacts moves more in ways in which people have created artefacts, ah, modern archaeology. And it was a little things like Alan Turing's computer and one helps in the war.

Ashley Fisher

Cool That actually sounds really interesting. Get exhibit. I'm gonna look that one up. That was the Barbican in London. Yeah. Wonderful, excellent. Yes. So if you remember any others, let me know. Thank you very much. Enjoy the rest of your day.

# 3. Amanda.

Amanda is a woman with psoriatic arthritis.

## 3.1. Pre-visit Interview.

I met Amanda at her home to conduct this interview on 8 November, 2019.

Amanda
The recording

Ashley Fisher
Oh, that's perfectly fine cat meows are completely allowed. Alright, so again, my name is Ashley, we've emailed a couple times. Yeah, and I just wanted to go over a few things to make sure we're on the same page before we get too far into it. So my research is looking at accessibility for people with hidden disabilities in museums and heritage sites. And you've been asked to be a participant because you have hidden disability, as I mentioned, we'll have three different meetings. One now, one, immediately after. Where we go to the museum in your case it's gonna be barley Hall, and I have a basic outline for things will do there. But by and large, I want you to leave the visit so I can understand how you experience a museum and how your hidden disability effects that experience. after the museum visit will go straight to a café or a pub or something like that, and have a chat about the experience as a whole. And then a few days later, we'll have our last meeting, where we'll talk about the museum visit again, and also about other museums and heritage sites that you visited and how they compare. That's all right. Good, excellent and we've done the information sheet and that. So I have a few questions for you. Once the kitty gets out, there you go, sweetheart. So, you mentioned that you have rheumatoid arthritis. Is that correct? Okay. And I've done it

Amanda
Well, it's under the umbrella of rheumatoid arthritis. Okay. My arthritis is psoriatic arthritis all based on psoriasis. Okay, so my parents have had severe arthritis so no severe psoriasis. Sorry, get it right. Okay. They had lots of skin problems. I don't have any skin problem. Okay. But I have the Arthritis that comes with that immune problem. Yes. System yes immune system problem. So my arthritis attacks, different things to rheumatoid arthritis. It's okay. So it's attacks cartilage, tendons and doesn't actually cause damage to them. It just caused lots of inflammation, inflammation and pain. And I get the general fatigue that all people with this type of inflammatory arthritis get. That's the you know, chronic fatigue is a problem.

Ashley Fisher
Yeah. Excellent. Well, that was my question. Yeah. So you're the expert. I've done a little research on it. Right is but I wanted you to explain it to me. And it's something that you're born with. Is that correct? Since

Amanda

it was Yeah, it's passed down by to you from your parents yet you get it from your parents. Okay. Fantastic. Excellent.

Ashley Fisher
Yeah. And throughout the day, or an extended number of days, how does it affect your daily routine? Yeah.

Amanda
If it's under control, it's not too bad. And I take drugs to keep it under control. I take two lots of injections a week. Okay, and that damps down my immune system. And that then means it's not attacking it.

Ashley Fisher
Yeah.

Amanda
But, I mean, I also have a second problem, which I would call it a disability. You know, I have heart failure. Oh, I have what I am being assessed but haven't been listed for transplant. Okay. So again, it's a it is still a disability. I would definitely Yeah. So I mean, that causes breathlessness causes lots of breathlessness and, and fatigue as well. Yeah. And so on a day to day basis. Well, I am now fully retired on health grounds because of my disability. And that's literally only just come through. I retired because I could No, I said the power need to retire actually. Carry on. Yeah, I'd already reduce my hours down to half time. Hmm. So that I didn't work full time. Sure had had assessments at work, too. I had a working pattern that allowed me days in between for rest days. Okay, but it was still not working for me. So I retired. And as part of my retirement, I said, I'd like to be assessed for retirement health grants, because I think that is, you know, what I require? Yeah. And basically, that just protects my pension.

Ashley Fisher
Gotcha. I was going to ask what's the Yes, the difference because clearly, I'm not from this country.

Amanda
So you say if you retire early, your pension is reduced if you retire before the usual pension age, but if you retire under health grounds, then that pension is as is as if you had fully paid into it the council continue to pay it.

Ashley Fisher
Gotcha. Okay, that makes sense. So, yes,

Amanda
so and then so on a day to day basis, and I don't get up as early as I used to do so I need extra sleep. So I even now need an alarm to wake me up more than when I was at work. That work pattern thing I was in was working but now it isn't. Yeah. So yeah, I can be feel like after I've been up half an hour. I feel like sometimes I just want to go back to bed. It's really hard. Really hard to push through. very stiff in the morning. I've got a right hip and my lower back. spondylosis of the spine is one of the side effects of this arthritis. My spines, lower spine is very stiff. And so yeah. So then as we get going things loosen up and you know,

378

Ashley Fisher
sure

Amanda
I need to keep the house really warm because I can't get cold. You know, I don't like going I don't go anywhere where it's cold. Yeah. If you somebody would say it shall we go down to such and such a) I couldn't walk because of my breathing. Yes, I properly wouldn't walk there today. It's too cold.

Ashley Fisher
It is. It's quite.

Amanda
So I don't do cold. I don't like going anywhere where it's cold. You know, so if the venue was cold, I would not go, or I'd leave early. Yeah. So I don't do cold. I don't. I always think about where, you know, there's somewhere sit down, because I don't have a walker. I think that's a bit of pride in me at the moment. I feel I want to go down that route quite yet. But I think it's you know, might do it at some point. Because, yeah, having somewhere to sit on going along. It's not a bad idea to be honest. I mean, my joints can be stiff and so difficult handles and you believe how many public buildings you know, hotels or whatever. These enormous doors that are so heavy they're always to pull. Never to push Yeah. And so yeah, that is just yeah unbelievable that. I don't do like heavy doors at all because my it's in my wrists and my fingers they're not as strong as they were sure. So that's difficult the steps of course any look lots of stairs, always will go for the lift Sure. And escalators or something like that. I have a blue badge for my car so I can park nearby things so I tend to use my car. I have got some what's called a benefit called PIP – personal independent payments, which is the mobility component of that. Okay, so that gives me some money towards using my car or any other transport, money to pay for Yeah, and again, I just will space things out throughout the week. I will never do two things in a row. For instance this week. On Wednesday day time, I was helping a friend or I was doing helping with the catering while her family were building a greenhouse, a large greenhouse thing. And I did that on Wednesday morning, and then I went home and Wednesday afternoon to rest because I have I do a bit of dancing to help my back. I do belly dancing, which is good for the back. Yeah. But in the end, I decided I didn't go to my dance and I was too tired. Because I've done that one thing. Yeah. in the morning. I thought it would be enough to rest up in the afternoon but it wasn't. So yes. So like my working week I tried to do one thing on one day, then have a rest day and then do something on another day.

Ashley Fisher
Sure,

Amanda
yeah. Just things that, you know, small things each day.

Ashley Fisher
I apologize for today.

Amanda

No, no, no. That's fine. Now I've already factored that in. Okay. I've got nothing planned for tomorrow. And yesterday I was I had something planned in the morning, but I wasn't doing anything in the afternoon.

Ashley Fisher
Okay.

Amanda
Yeah. So I've already planned that in when you asked.

Ashley Fisher
Yeah. Thank you very much for that.

Amanda
Yeah. So no, that is important to me to plan things so that they spread out. Yeah, and it's just the problem with this. These sorts of inflammatory arthritis is you never know from day to day, when you're going to get arthritis, some sort of flare up, or the fatigue is going to hit and I was a little bit worried when we've made this day because last week, I was just in a fog all week. I know I really am struggling with fatigue and tired It's Chronic Fatigue is you know, it's not just feeling really tired it goes beyond that you can't function you can't think your brain just doesn't seem to want to. to work.

Ashley Fisher
Yeah, yeah, I have. I'm on medication for depression and I also have iron deficiency anaemia right now so I fully understand that. Just I'm so tired. I can't even watch TV right now. No, yeah, exactly. Yeah, yes.

Amanda
Yeah, absolutely. I yeah. And the game you know to fix your iron levels that medication my mom so I have iron infusions. No iron tablets, awful things

Ashley Fisher
do not like

Amanda
excellent. And

Ashley Fisher
for today, the visit last as long as you want it to there's a couple things that I want to make sure we hit but they're really simple things like that. Obviously, going to the admissions desk, checking the toilet Yeah, visiting a particular room that the on the ground level. So yeah, we don't need to worry about that and buying something from the shop. Yeah, I have five pounds, so you can use that. But it can last 20 minutes if you want it to, it's totally up to you fine. Okay. For the most part, I'm just going to be observing you as we go through the motions of everything.

(Think aloud technique practice)

So I'll ask you, hopefully a couple times during our visit, to just think aloud. Yeah. Going around. And now you know what to do when I say that

Amanda
just thinking through is just as you're looking at it.

Ashley Fisher
Yes, exactly. Alright, so let's talk about how you prepare for a trip. Do you do any research ahead of time have a place?

Amanda
Not necessarily. I mean, I've been to Barley Hall before. I went a couple of Christmases before to one of their special evening events where there was some carols and some food and drink. Yes. And so You know, and that was just in a brochure of Christmas music. So I just selected it and we toddled along with a couple of friends. I tend to go with friends when I'm visiting someone. And so you know, we did a house and garden recently is [Burton] Agnes Hall. And we went there and I knew a little bit about it before going, but I didn't really know an awful lot. Often I could might be influenced by something I've read in a magazine or newspaper or seen an article on TV. Something about the place that I think Oh, yes, I'd be interested in going to that. Oh, yeah, I'd like to go see that particular painting, for instance, in a particular place, or the garden that's been recently made over to into certain scheme and I could look at that, as opposed to just saying, I'm going to go to X. I'd go to X because there was something I particularly wanted to see there. Okay. I have to say I don't go. I mean, to a lot of I'm annoyed that the art gallery is no longer free and that you have to pay for it. Yeah. But now that I'm retired, I think I'm, I've been retired now. Well, I haven't been to work since the beginning of September. I am reviewing things. And as I said, over these last couple of months, my financial situation is improving slightly so I may well, you know, review how I pay for things, but before when I was working, and I had more outgoings and things like that. I was annoyed at having to pay to go into the art gallery. You know, now I've got time I think I might not. worry and I got more finances, and I thought I would have. I might not quibble at paying. Sure. But yes. A lot of the time to Like, you know, residents weekend and things like that. I would plan a thing, Yeah, I'm going to do that. I'm going to go to a couple of those things this year. And then the weekend would come and I'm feeling lousy. So I will get.

Ashley Fisher
Yeah. Yeah.

Amanda
So yeah, so sometimes I think I'm going to do something and then it doesn't happen. Yeah.

Ashley Fisher
All right. Are there any specialist equipment or aids that you bring with you or anything like that?

Amanda
I'm not really know. I mean, I do have a special cushion for sitting down on or any cushion because I really, really don't like hard chairs. Sure. The tendon at the top of my leg is always very tender. And sitting on hard surfaces is not good. So I might bring it with me if I remember. So part of my problem is that I'm so I think that's partly with being at work so

used to just going on this track that I forget the bits that I can do. That helped me. And I get there and I think Oh heck I forgotten such and such.

Ashley Fisher
Yeah, yeah. Do you think that might improve over time as you're adjusting?

Amanda
Yes. Okay. I think now I'm, you know, planning things for myself from home. I'm getting better at it. Yeah. Okay. Bit more time to plan things. Yeah.

Ashley Fisher
Do you ever check out of a museum or heritage sites website before you go?

Amanda
I haven't done okay. I mean, but that's completely fine. You know, to me, but that's not to say that I'm you know, now that I've got my I was without a phone for ages. Well I did have a  phone, but it wouldn't connect to the internet or anything. Yeah. But my I will, you know, I'll sit here and I'll be having a conversation with my dad and will say, hey, so such and such and I'll straightaway go and look it up and see what you know, to So now my phone is more active then I do tend to look at things so if I hear somebody mentioned something I don't know, straightaway look it up Sure.

Ashley Fisher
Do you plan for any eventualities or emergencies But no,

Amanda
no okay No, I'm a very spontaneous person so I don't think I do plan for you know what my Tony to see I always forget to take a bottle of water You know, I need to get better at that. Yeah, I do always have a make sure I've got some pain relief in my bag. So do I suppose I do in from that respect? At least I have something in my bag. I need to take a couple of tablets.

Ashley Fisher
Yeah. And how much time does it take you to get ready for just going out?

Amanda
Not long. I usually start the day dressed for what's coming up? I don't need to go change and then I just need to grab my bag. Make sure I've got the keys. I am very bad at leaving my house keys so I've got two people with a spare key because I locked myself out. But yeah, and then just hopefully just go through the you know, grab this grab, grab, grab a bag, grab the phone, half the time I go out without my phone. Yeah.

Ashley Fisher
Alright, so for the visit itself, we're going to do what we're calling a semi structured visit. That means that we follow your lead we just you can go wherever you want in the museum spend as much time as you like there whatever you want. I want this to be as normal a visit for you as possible. That being said, there's a few basic points I want to make sure we hit so for. For barley Hall, I want to make sure we visit the Great Hall which is like the second room that you see. asked the member of staff for help, purchasing small item in the shop and visiting

toilets. So yeah, fairly straightforward things that most people would do on a visit anyway, just want to make sure that we hit those things. It's easier to compare the different visits. And then after the museum visit will go to nearby pub or something. Yeah, have drink and snack and have a little bit of a debrief. Yeah. Excellent. I have a few questions for that. And I also want to do it while I'm calling a visit audit. But I have a sheet to go through that with you. So don't worry about that. Yes, so things like noise and light levels. How easy to read signs are you have enough seating, things like that? That sounds excellent.

Amanda
Yes. Wonderful. Yeah. I'm just debating. And I wear glasses. Okay. Sometimes I wear contact lenses and then now I'm just debating whether to contact lenses. I think I think I'll take my glasses. Okay. So it's when I'm reading things Which is better to me? Yes, I think my glasses are better.

Ashley Fisher
Okay, excellent. I have contact lenses but I have really terrible vision so I have to wear them all the time. Yeah. Excellent. Well, that's all I have for this part. So Okay, you ready? We can

## 3.2. Site Visit.

Our visit to Barley Hall took place on the same day. Due to a technical error, the audio recording did not work.

## 3.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
Excellent. So we're going to go through this section right here. How easy was it to find the museum?

Amanda
 Fine – I know it's down Stonegate, so I mean, I don't know or remember which alley, but I know it was Yes, I did. I know vaguely where it is. And if I didn't know where it was I probably would look for it on my map [on her phone].

Ashley Fisher
was it easy to find the entrance itself once you got to the building?

Amanda
Yes, yes. Yeah. Right. It was obvious.

Ashley Fisher
Yeah, yeah. How was the layout of the museum Was it easy to understand, difficult to understand?

Amanda
Difficult from the point of view of it didn't flow from one to the other okay, you had to find where you were, yeah, you know find the signs by the way yeah. it's quite a small site. Yeah.

Ashley Fisher
In the shop, was the signage easy to understand?

Amanda
The shop was bit strange. I always find gift shops in museums a bit strange because you don't know actually what they're going to be selling. And in what way they're going to link it, so it's a case of just wandering around and seeing what they got.

Ashley Fisher
was there enough space to move around the shop?

Amanda
Yes, yeah.

Ashley Fisher
And was it easy to navigate the shelf?

Amanda
Yes, yes. It was all sort of circular.

Ashley Fisher
Now you visited the toilet so were the toilets easy to find?

Yes. Good. Was it clean?

Amanda
Yeah

Ashley Fisher
and was the floor especially clean?

Amanda
It's been a wet day, but I think it was relatively clean.

Ashley Fisher
All right and did any of the staff members- Do you feel that the staff members treated you any differently than another visitor?

Amanda
No. Probably because they didn't necessarily know I had a disability. I don't have a cane or anything right.

Ashley Fisher
That's my next question. Do you think they would have treated you differently if you did have a visible disability?

Amanda
Okay, they might have asked, do you need to see, find anything. That sort of thing. Potentially they could have done. Yeah. Okay.

Ashley Fisher
Was the team member was able to offer the appropriate help when you asked for help?

Amanda
very informative I'm glad I

Ashley Fisher
did you feel welcome there

Amanda
Yeah, they were very friendly, I mean there weren't many staff on view, yeah, yeah but when they were around, they were very friendly.

Ashley Fisher
normally there's only two people that are on staff: the manager of the day and then a front of house that's on admissions till. Sometimes on the weekends we'll have some costumes interpreters but right yeah, yeah and sometimes volunteers as well. Yeah. So the exhibition where the displays clear?

Amanda
not always. not always okay. I found it difficult to read the white print on some of the backgrounds. Some of them were not as well lit. yeah

Ashley Fisher
alright were the fonts easy to read

Amanda
Not necessarily

Ashley Fisher
Not the best How do you feel about the colour contrast on the signs?

Amanda
I prefer just plain black on white. Okay. Okay.

Ashley Fisher
All right. Um, there was only one video that I remembered in the entrance room – was the volume at that a good level.

Amanda
It was, I listened to a little bit of it, I was reading the timeline. Sure,

Ashley Fisher
where the stories of the experience and of the exhibition easy to read and understand

Amanda
I wasn't sure I got the full story of the house. Yeah, what it would have been like to have lived in that house. There were little bits of information dotted around, what they were eating, how it was prepared. I don't know if I got a full picture as to the story of the house.

Ashley Fisher
How as the over all noise level there.

Amanda
It was fine. It was a very- I mean that group that was in wasn't very distracting

Ashley Fisher
Yeah, they're actually really well behaved

Amanda
They were fine.

Ashley Fisher
were some places too loud?

Amanda
No, it was fine

Ashley Fisher
any place too quiet

Amanda
No, I quite like quiet.

Ashley Fisher
and what about the lighting levels.

Amanda
They, yeah, there were some places where I couldn't quite see and also you know, I like to see into a room – I have difficulty stepping into a room, so I do quite like to see what I'm stepping into this Yeah.

Ashley Fisher
Do you think there were enough places to sit or rest?

Amanda
Yes, there were benches placed around the place which you could sit on. That was good

Ashley Fisher
Excellent. All right. So looking at the Great Hall, yes. Where the displays clear.

Amanda
Was that the one downstairs?

Ashley Fisher
 yes. It's perfectly okay to say no,

Amanda
no, I'm just trying to think if I noticed them.

Ashley Fisher
Yeah, I'm trying to I don't think that there's any signage in the great hall. It's just lots of stuff on display. Yeah.

Amanda
I mean, you saw things on display. I think that room is more about just getting the feel for the place. I think it just calls itself the great hall. Yeah. I mean, there was no it didn't say you know, this is a fireplace, you were sort of left to figure it out, I suppose.

Ashley Fisher
Do you like that or would you have preferred more?

Amanda
I could have got the booklet at the beginning, maybe that might have told me more. I saw a gentlemen going around with it. Okay, yeah.

Ashley Fisher
Oh, right. Was the lighting level in that area All right?

Amanda
No, it's fine. That was fine. Okay. Don't know if it's because of the glass wall.

Ashley Fisher
It probably helped. Yeah. Alright, so now just some general questions. What is one good thing about the museum just in general?

Amanda
Easy to get to for me. Okay. Where I can park near to.

Ashley Fisher
All right and one bad thing about the museum in general.

Amanda

Things were not easy to read.

Ashley Fisher
And that's because of the combination of low lights, not the Greatest colour contrast. Yeah, it's not one specific thing. It's just

Amanda
Yeah, lots of things.

Ashley Fisher
what's one good thing related to accessibility or disability in that museum?

Amanda
toilets on the ground floor. Okay, right. Easy to get- the door was easy to open. You know?

Ashley Fisher
Yes, yes. All right. And what's one bad thing about accessibility at the museum? What's something you think they can improve on?

Amanda
Oh, I see. Yeah When there was steps and things such steep steps, to get something like a grab rail. I wouldn't want to detract from with the home but something that was able to get a hold.

Ashley Fisher
yes I'm positive we could find a solution that is in keeping with the rest of the house

Amanda
Yeah, yeah.

Ashley Fisher
All right did any particular barriers jumped out to him? That made it even more difficult for you.

Amanda
the tiled floor in the Great Hall, it was sort of uneven and Okay, you know, I do unfortunately I can stumble easily Yeah, with walking you know, anything you know, it's just have to be, I was aware of having to be careful.

Ashley Fisher
Were there any particular accessibility tools- that would have been helpful in there. Like maybe a one of those walking frames that turns out into a seat or a handheld cane or handheld lantern or something like that.

Amanda
Probably wouldn't.

Ashley Fisher
So a walking frame, grab rails, and raising the lights in general

Amanda
yeah

Ashley Fisher
Is there anything the museum could design into the exhibitions from the very beginning so like making sure that their fonts are a bit better and colour contrast

Amanda
Yeah, those sorts of things. Yeah. And maybe as I say, you know, information things in as you entering Yeah. There were one or two of those tablet type things, so if you hadn't purchased the book, it would be quite helpful. So say somebody you could pick up as you went in the room. That says the room you are now entering is such and such, been used for.. over the centuries it would have changed from X to Z. Yeah.

Ashley Fisher
And I saw you use your cushion a few times

Amanda
yeah with the hard benches around, I quite like to have that there.

Ashley Fisher
and how did the staff make you feel?

Amanda
They were friendly. I think the faff with the tea towels was embarrassing, I was in the shop I would have tried to do the transaction for the cheapest and then sorted out the issue later. I mean if I if I'd been here people behind me I might just stopped and said oh let's not bother. yeah

Ashley Fisher
If you could tell them you see one thing regarding the accessibility of their site, what would it be?

Amanda
Well I understand that in York, in an old city, a medieval city, you know there are cobblestones everywhere. It's not easy and I think I would accept that Yeah. Yeah. I accept that it's part of these places. I can't remember now but not it was like a step over it probably was, It was I can't remember. Yeah. Sometimes they go to that other end, they overcompensate and it does take away from the experience of wanting to experience you don't want it to be to, you know, you want to feel like you're going to somewhere different. Yes.

Ashley Fisher
So would having that ramp there all the time. Would that have taken away?

Amanda
Yes, yeah.

Ashley Fisher
Okay.

Amanda
Yeah. It was useful that day but you know, a grab handle or something would help.

Ashley Fisher
Right so anything else that you want to mention?

Amanda
[chat about the purpose of Barley Hall as an education tool and its lack of 'star item']

Ashley Fisher
So would you visit Barley Hall again?

Amanda
No. I'd go to special events, maybe. Unless of course I had somebody come stay with me particularly interested. Okay

Ashley Fisher
That is all

## 3.4. Follow-up Interview.

We met at Amanda's house on 19 November, 2019 to conduct this interview.

Ashley Fisher
Alright. Excellent. So

How were you feeling the next day after?

Amanda
So I got back here that afternoon as you say it was cold. So I think I think the rest of that day. what day of the week was it eight

Ashley Fisher
was excellent question. I no idea. I think it was a I want to say Thursday. I think it was I

Amanda
No, no, I think it was a Friday. Yes. It was a Friday because I had nothing else to do so that was quite nice. I think I just relaxed for the afternoon to be honest when I got back, okay, which is what suddenly after some an activity That is what I do. Yeah, I wouldn't do anything else. And by Saturday, I think I was probably fine.

Ashley Fisher
Yeah. Didn't have any, like, any negative side effects or

Amanda
No, I mean, I'm, if it was, I mean, I've been I've not been very well I've developed other problems might be doing to my arthritis. So I was poorly on Saturday, but I can't remember if it was that one. Sure.

Ashley Fisher
But now I wouldn't have linked it going out.

Amanda
So, yeah, so now it was fine. As they say, for the rest of the day. I didn't do anything for the team.

Ashley Fisher
Okay, so one of the things that you mentioned was that you wanted there to be more accessibility. Things like grab rails and things like that, but she also didn't want it to take away from the atmosphere. Yeah,

Amanda
yeah. Yeah. So I hadn't thought of something the other day, we Yeah, I think it's somewhere else. Something like a rope a nostalgia room. Oh, yeah, I think I thought you bet. You know, it would have been a useful thing for just pulling me up or something. Yeah. Yes. I can't remember what why that came to me. When I was thinking about getting about Yeah. Also, where my shop I work in, we have a very steep step down to a different level in the shop. And so for accessibility for all our customers, we have a grab rail there. And I use that I myself got something in the other hand, yeah. So yes, that's a witness all that graduated I thought you know about things that we could use. Yeah. And I thought that the road route was brilliant.

Ashley Fisher
I've been trying to picture you know, a piece of wood or something that just sticks out a little bit from the doorway wasn't quite working in my head. Yeah, but no, not broke. actually sounds. Written if

Amanda
you could just grab it and just stare at you and pull you up if you're going out, and it doesn't, it's not super stiff in there in the way. Yeah, exactly.

Ashley Fisher
I like that idea. When you go around a museum, would you consider yourself the kind of person that reads everything or just kind of looks at things and reads here in there.

Amanda
So if I were to go to an exhibition like I went to the Pompei exhibition museum A few years ago, I would read everything because you as much as the crowd allows, of course, get the quite busy, but there's a special tech ops that got, you know, artifacts from all over the place which you wouldn't be able to go back and see when you know, they're also telling you a bit

of a story, the storyline usually going on in those places. So in those places, I would tend to read everything if I was going around somewhere buttonhole were probably I know a bit about medieval history of Europe because it seems that the local press all the time you know various places pop up here and there you know I go to them on like I said I went to a nice musically mean there gives me I might not read so much of all that stuff but it so unless the exhibition interested me I would read it otherwise I wouldn't really necessarily offer. Yeah.

so but yes so what do you say for instance go around the auction Museum, I might read the bits that interest me that the artifacts that I would I wouldn't be interested in this is stuff that I might not be interested in seeing war things but actually I quite like war. But things that might not grab me so much to go for. And I like to look for my favourite thing. Go back some time. See it's still there.

Ashley Fisher
Yeah, correct. Yes.

Amanda
I do tend to read labels. So I do like them to be able to see them easily and work out. Even the ones that have you know, went them in cabinets. It's not always easy to read them. So sometimes it's quite nice. I went to a nice Museum in Hania on Crete. Okay. Really nice, ancient Romans, you know, written ancient stuff, Greek and Roman stuff. There. And, you know, you might get a postcard with the information on in that sort of thing. Yeah. So you can say this. I saw that and it's, you know, remaining 2000 bc and what have you?

Ashley Fisher
Yeah, yeah.

Amanda
Got a box full of Postcards from all the places I visited. I did

Ashley Fisher
see your

Amanda
postcard. Yes, exactly. Yes. So yeah, I've got them from loads museums. Yeah, I keep everything. Just sometimes. The postcards, I can send us a card to someone. Yeah, to say hello. But sometimes I just keep them because it's quite nice.

Ashley Fisher
Yeah, absolutely. We've been talking a lot about the temperature of day you think that had an impact on?

Amanda
Yes. Yeah. Perhaps if you know, we haven't arrange that day and I was thinking of going. I would put it off.

Ashley Fisher

Yeah. Okay. To another day. That was another question I had if we had taken this trip on a particularly bad day, for arthritis

Amanda
Oh yeah, yes. Okay my arthritis was flaring. Yeah, yes I would because I would just be miserable I would be bad company. Hi. I wouldn't be able to enjoy it as well. Yeah Yes, I have I mean I've cancelled a weekend in London when I was going to stay with my niece my apprentice. Yeah, I do have to cancel things. But yes, although my niece in London her husband worked at the British Museum and which is quite new to Kings Cross Station. So they were always very good like meeting me. Or you know, even off the bus over to because said I was okay to go that far. But like when I was going home, and I want you to Curtis British Library to an exhibition. My nephew Loki took my case. met me at the station was very, you know, it's nice to be able to plan things with people, you know around hell. Yeah. So you know, so going to museums and things. It's quite nice to go with someone else. You know, so that if you're not feeling great, you know you you've got somebody I know I did the pump exhibition with a friend of mine, Joyce died from cancer. But yes, that was a nice day out with Joyce and even though it wasn't her cup of tea, she was very, she very kindly said he come. Yeah, you know, to support me so yes, I do like to have somebody else there.

Ashley Fisher
Yeah. So you often go to museums with the least one other person. Yeah, yes. Yeah,

Amanda
yeah. Yeah, yes. Nowadays. Yeah. Me before. Yeah.

Ashley Fisher
We also talked about the lighting quite watch you think it would that? Try that again? Do you think that the temperature or the lighting had more impact on your visit?

Amanda
temperature? temperature? Yeah. Yeah. Yes. The lighting to read things was a great moment. I mean, it was a dull day. Well, it was quite overcast that day. Yes, I think that may be you know, as I say, in some places, of course, they can't buy things very brightly because of conservation with the objects or whatever. So that's when it's quite useful for me to have an information sheet for that route. Yeah. Which you can then take to where there's a good light to read. Yeah.

Ashley Fisher
And you said you likely wouldn't visit Barley Hall again.

Amanda
Not to say I had a visitor who was very keen to go from there quite happily go with them. I wouldn't necessarily go back myself now. If there's an event going on it's quite nice to be able to go specially into the whole main course. But yeah, as I say, there's so much stuff in New York you can just fall over it you know, my little shop I work in next door to the merchant adventurous the building I work and it's all you know, pretty old. Yeah. Oh. So this plenty you can actually see and bumped into without actually having to go back to one particular place. I felt when I was going around follicle. It seemed more than like a museum at the auction museum where you go to the story of your co Particular artifact you may be wanted to see that image of jewel. barrio was like a resource for schools because it taught

393

the story of the Middle Ages very, very easy, compact way. Yeah. And I think not good also for tourists, you know who don't make it come from a city which is full of evil stuff. Sure. It's an easy accessible way of gaining information and, and an experience of a medieval home. Yeah. But it seemed a more of a resource, an actual venue, it's a great place to go. And also, I think, if I was compared with what I did a few weeks ago when I went to Burton, Agnes, which is gardening friends and we were going particularly for the garden as well as the house So, if you get two words not to one as such, because you pay for them both, but sometimes you need to combine it with a garden as well. Hmm. And also the home was lifted.

Ashley Fisher
Yeah.

Amanda
So that's, you know, it's another thing you know, as the people, the guide, so curators, whoever they are, who are hanging about place, say is, you know, come by the program, we shut the door, we take out these ropes from the family moved back into these rooms, you know, yeah. So a place that's lifted, as well, I think has a deeper connection somehow. It's, it's, you know, it's been like that all these years. It's had a history of its ups and downs, but the family is still there. And it's just thinking you know, the, the ladies room so loud or whatever you It's been bad or furniture in it at some things that sort of give you the experience of what it was. Because the only room that had that to be truthful was the main hall, isn't it? Yeah. And maybe some of the kitchen areas you know where they put a few pots, dishes out. The upstairs rooms pop from one chest seat. Yeah, there was nothing there. Because I remember visiting Richmond castle what which one anyway, Mary, Queen of Scots. And, allegedly This is how bad it was always quite interesting.

Ashley Fisher
Do you think there are different expectations put on pain versus non pain?

Amanda
I wish our gallery was non pain. I will be somewhere I would go to I think if it was non paying, yeah. I suppose you know, I'm retired I become a member, a friend dog and you know, we have to go and access it that way more often, maybe this year. So I mean, the non paying ones tend to bigger. Be honest, like the railway museum and you know, people from all over first, maybe this is where you have to pay a smaller. maybe don't have to wider retraction. Yes, it is harder for them I'm sure to make their way and to get people in to make you pay its way. In a way, you know that we sometimes I see programs on TV, somewhere up in Glasgow, some great big Art Gallery, which is fast enough all sorts of stuff in. And I just think that must be just such a thing to be able to say, Oh, you know, Sunday afternoon, it's all just crammed down there and see what's going on. And families don't have to think about all that. You know, we've got three kids and we've got two from next door now. It's still that critical. We could just go down there and have a great time. And I think that's what's so good. You know, I mean, I used the railways here when I was looking after my friends, children many years ago. When she was working, and you know, he just knew that that was a place you could go and they would enjoy it. And you could have a good look around at the same time. And yeah, and it was great. But you wouldn't be able to do that with children for instance, if you are paying all the time. Yeah. And I think as a city we don't apart from the railway museum that is about the only place that's non paying. So you know, when I go to London, you just go around the mall? Yeah, go to me, various ones. And I don't mind paying for special exhibitions because you know, that she has I've had to bring things in from all over the place. And it sounds really interesting. So yeah, I mean, I quite like Chris Michael to

get out to them because of the one of the fish museum. Troy Yeah. But no, it's normal. penguins. I think I would go to more of a having said that I have been to the museum for ages to walk. Yeah, it's quite big.

Ashley Fisher
So my last question is quit personal one. So feel free to say you don't want to. Do you consider yourself disabled?

Amanda
Definitely. Yeah. Yeah, there's no I mean, yes. Yeah, I mean, I've retired on health grounds. My health is not good. And yes, and it's, it's a really difficult one, you know, I thought I was posting a letter yesterday I was in the car outside the West offices where I used to work and I saw a friend and the walk down the window and she was look somewhere and that's what sets difficulties you know, yeah. Yeah, really hard to, you know, get through the day sometimes. You know, worry, you know, now our marketing was gonna be that it's gonna be okay. For a few weeks to know how quickly can we go to Syria, right? Yeah, it's lots of things to think about. Yeah. So yes, I do definitely, you know, I don't feel any guilt. Now. I used to, you know, with my blue badge and popping out five things. You know, I do find it restricts how I can get about, you know, planning things like a trip to London is no longer just like Oh, can I be a couple of weeks time?  You know, I don't know how I've been feeling. Yeah. The holistic Council. Yeah. trip to London that long ago. So yeah, I do very much feel my health conditions are disappointed to save me from being able to share. Yeah, you know, act behave like I used to do.

Ashley Fisher
Yeah. Yeah. Would you consider yourself a disabled person or a person with a disability?

Amanda
person with a disability? Okay. Yeah, yes, definitely. Yeah.

Ashley Fisher
There's very interesting debates and disability studies as to whether the general preferred term should be disabled person or a person with a disability. And yet once you start actually looking at the nuances, it's very interesting that people with visible disabilities prefer to be called disabled people. Yeah, people with hidden disabilities very much prefer to be here person to the disability. Yes. And I think it's very much lost in the Raider compensation. So, very interested this particular question.

Amanda
Yes. After rematching Yes. And yes, you know, somebody in a wheelchair has no use of their legs is a disabled person. Yeah, you know, they might have had an accident or whatever, and they're now disabled. Yeah, they may have been born like that, and have lived with a disability or lack and they are disabled. But there was a lot of us, the things have crept up on us. And we live with whatever it is, particularly when it isn't there all the time. You know, things like my arthritis, you know, has flare up and I'm good days and you know, be fine. And then then I will have a number of days when it will just feel dreadful, and that's when it's flaring. And that's when I know my arthritis is not good.  And my heart is a different thing altogether. Stop in my tracks all the time. Yeah, just about, unfortunately. But yes, no, you know, I have someone who has acquired, you know, various things. And that caused me to now have a disability that I'm living with. Very good.

# 4. Amy.

Amy is a woman with anxiety, hypermobility, and OCD.

## 4.1. Pre-visit Interview.

I met Amy at a café to conduct this interview on 17 November, 2019. The audio recorder stopped recording after the first few minutes, so I emailed her the questions from the interview to have her exact words. The email follows.

I've known I've had anxiety since a young age but as a child I didn't really understand it. I just thought I was a 'worrier'. After a bout of bad mental health when I was an early teenager I was diagnosed with anxiety and then later OCD. It's very hard for me to be able to tell the difference between the two so I'll just describe them as one. I frequently get into thought spirals where I can't control what I'm thinking, sometimes these lead to me having to act on these thoughts but often they don't, it depends on the nature of the thoughts. When I do have to act on them they're almost always about organisation. I often have my day planned by the hour for weeks ahead of time (I currently have until a week on Sunday planned). I will often do things like decide I'm going to do something next week and I can't stop thinking about it until I write it down in my plan somewhere. I will also often need to do things last minute but have the inability to do them until I've worked it into my plan, and will refuse to do things that I actually want to do (such as seeing friends) because it is not how I planned the day to go. Something that causes me a lot of anxiety is other people's health, I often get into thought spirals that lead to panic attacks where I am convinced that someone I love is unwell or in danger. These are extremely damaging to my own mental health but also to my relationships because it's a lot of pressure to have to deal with in the moment, especially when I'm directing so much anxiety and panic their way. One of the other major ways it affects my life is food. I have a lot of OCD surrounding food that has existed for as long as I can remember. I'm afraid of contamination and find things like washing up other peoples dishes difficult (and sometimes my own). The main issue is that I have a very short list of 'safe foods'. Everything else I can't eat. This is difficult to explain because it's not just a 'I don't think this' but it's like my body can't accept that it's food. I will really physically as well as mentally struggle to eat these foods. This doesn't bother me as much because I don't feel like I'm missing out on foods as my brain has a hard time even accepting that it's a thing that can be eaten.

I was recently diagnosed with hypermobility syndrome as it took me a long time to work out that what I was experiencing wasn't the norm. For as long as I can remember I have had joint pain. My ankles and wrists would constantly ache as a child and I would tell my parents about it but it was constantly dismissed as 'growing pain'. I get frequent subluxations (partial dislocations) in my fingers, wrists, toes and knee. Over time these become less painful but I have clear memories of being in agony as a child due to knee and toe pain. I now recognise these occasions as early subluxations. I would say things like 'my ankle hurts' to teachers in PE and they thought I was trying to get out of sport, or I would borrow my dads wrist brace a lot and my dad said I have carpal tunnel but my mum thought I was trying to 'look cool'. As I grew older I would tell my mum that I don't think my hips look right and I was getting a lot of back pain and rib pain. She told me it was normal and it was because I was sitting at the computer for too long. It turned out I have a scoliosis caused by my hypermobility and that all my joint pain wasn't normal. It took me till getting to university and learning about other people's experiences to realise this. Over the past few years I also believe that it has gotten worse. I am in almost constant pain in some way, and although this is usually quite low level it causes chronic fatigue and brain fog which mean I can get easily overwhelmed and my pain/fatigue levels can quickly get out of control if I don't manage it. For example I can stand

for long periods of time however the pain it causes will likely mean i can't do much for the rest of the day, I can sit down for hours at a time but it will likely make my back sore and keep me awake at night etc. It's something that I constantly have to think about and adapt to. It's also something that I really struggle to admit to myself due to being dismissed for so long.

Due to the need to plan I will likely look at a museum a long time before I plan to go. I will have made plans with someone to go and I will know exactly how to get there (though due to the compulsion to constantly check things before I leave I am often late to things) and where we're meeting etc. Most of the pre-planning is spent working out how to get to a place and where I will be meeting someone. I will find the way that requires the least amount of walking and if there are long periods of walking that are unavoidable I will look into getting an uber some of the way or find out if there is a café or somewhere to rest inside. Cafés are often something that I look for because having small snacks throughout the day is something that helps my fatigue levels (I also have low blood pressure caused by hypermobility so it's better for me to have small amounts of food throughout the day than eating bigger meals). If there isn't any cafés I will look at the rules of taking food inside so I can take plenty of liquid and enough snacks. I will sometimes look up how long the museum would take to visit so I can work it into the plan for the rest for the day but also work out what I need to bring with me. The night before I leave I will have everything ready as I struggle in the mornings due to fatigue but also this is an OCD habit that has developed over the past year or so. Something else I will also check is the prices and if they do a student discount so I know if I need to take a student card.

## 4.2. Site Visit.

Our visit to Treasurer's House took place on the same day.


Amy
I didn't know about the eyes until I saw this but now I want to find the eyes.


Ashley Fisher
I like them but they're also quite creepy scary


Amy
I like the question mark there like why? I supposed if you have in your house, nobody's gonna talk about any other bits. Just gonna be like he has to be a total like mess. You're just gonna be like...


Ashley Fisher
The chairs have eyes Interesting the first person that's figured out


Amy
That I can sit here. they've made it look like it's part of the room. Which I understand why they would do that but also it means that I'm like...


Ashley Fisher
That is something that was remarked upon


Amy

I know I can't sit on that, but this...


Ashley Fisher
I think after a while people just give up


Amy
I like these


Ashley Fisher
What do you like about them?


Amy
I like that I can pick it up and take it around with me So I don't feel like I'd have to stand in front of it or take it away from everybody else. Okay.


Ashley Fisher
Excellent.


Amy
This one isn't too bad. It's quite well lit, like the other one... I know I was definitely going to get a headache if the rest of it was like that. I know it's not anything to do with me being difficult.


-


Amy
No, I didn't know that. I'm going to sit down


Staff member
So I'm going to come... [talking about Frank Green buying up old houses that were going to be demolished] Whether it was preservation because of the culture of...  don't know. Yeah, it's


-


Amy
I like this (banister edging)


Ashley Fisher
What about it?


Amy
I like that I can lean against it. It's very helpful. Yeah.


Ashley Fisher
Yeah.

Amy
Probably shouldn't, probably not... sturdy enough. Yeah, yeah. So this is annoying (garland on banister). pretty, but annoying. This is something else that I get, the fact that I'm walking up the steps but I get dizzy

Ashley Fisher
Is that a blood sugar thing

Amy
I don't know. Yeah. Maybe the bed is the thing [causing the sag downstairs] we are probably over that we are right now, but I think it might be. Yeah, it might be that one on the back. Yeah. Hear loud on that one. You know why?

-

Amy
I was like What? I am bad at directions. Yeah, because we can. Oh, yeah, right. Oh, yeah. Oh yeah, I see.

Ashley Fisher
I could feel it for sure.

Amy
I'm just very bad at directions. It just when we came around the staircase. Yeah, disoriented. Yeah. Really enjoy things like that but I don't know why.

-

Amy
Just want to lay on the table, but it's probably not...  Good idea, especially when the stairs was so not... They're not even shallow Oh, yeah. I'd rather they were shallow than like the one and a half step ones, they're the worst. did we go in here? Yes, we did. Yes, we did that count. Really appreciate all the tiny little creepy things on This is really pretty (garland on the banister). It's annoying that it means I can't put my hand on it, so I just thought I'd share that opinion. Well, that wasn't intentional. So conscious decision. Okay. No, that's my favourite one. Look at one oh my goodness. Does that mean this was an extension or does he  just like having windows? Well

-

Amy
I could spend all the time here. I'd changed this pink carpet. Yeah, the cream's a lot better. I mean, I realized that this isn't aimed at me but I'm going to point out that it was quite difficult for me to get out on the floor. I mean, it's probably in the people who are shorter than me quite yet also. Yeah, but also like, why don't I get to enjoy it?

## 4.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
How well do you think things were signposted?

Amy
Ummmmmm well there was a signpost but it's not really easy for us to find other. [It helped that they said they were next to the Minster]. Yeah, just looking already right next to it. Right there was a really important sign once again, but ...

Ashley Fisher
And how easy would you say it was to get around?

Amy
Oh, not the best. I enjoy having a walking system [aka defined path to follow] because I enjoy not having to make any decisions and I enjoy where I can making sure that I see everything that the museum wants me to. And in some ways there was a pretty obvious path but in some ways it wasn't – there was quite a few times I was like have I been in there in that have I not. This is not a major thing but like I would prefer there to be like [a suggested route] I don't know if that's very possible in there. some places where a lot easier to like the big staircase that was okay, like it had the left hand railing, though it was annoying that they had the wreath over and some cases were less easy like the second staircase so we went up.

Ashley Fisher
From the Great Hall to the gallery.

Amy
Yeah. it was like if someone is- because it's quite small, it someone coming down, It's hard to like- which is why I let those other people go in front of me because I could be quite slow right. And then the last one as well from the gift shop again that was like you can't really have two people passing and that was a little bit more difficult to walk down but it did have good bannisters, I'll give it that. Yeah. But yeah, the rooms themselves were pretty spacious. There wasn't really like anything massively in the way there wasn't really anything where I was like oh, this is physically difficult to get around. The one where all those family portraits were, it was a little bit smaller, a little bit more awkward to get around the table so there was like way... like a bottleneck. Yeah. Which I think is important to me because I don't want people to be stuck behind me.

Ashley Fisher
Something you're quite aware of.

Amy
Yeah. When like, if people can You know if people are still behind me, but at the same time, if I was stuck behind someone else.. I just think like if someone is – someone is like slower than me going up the stairs it's, it's also difficult to be behind them. Like I have to go to the speed that I go, if that makes sense. and slowing it down and speeding up this painful so like

if I can't get around someone, of if someone can't get around me. Yeah, both of those all like relevant.

Ashley Fisher
Okay so now we're going to go through the visit audit. So a lot of these are yes or no questions but was it easy to find the museum from the street?

Amy
There was a signpost but it's... I'm not 100% sure it's like anything that I can really credit to myself because it was just like where it is – like it's not the easiest to find.

Ashley Fisher
Was it easy to find the entrance from the street?

Amy
No, I didn't immediately know where it was until I saw you walking that way and I was like, oh, but if I suppose... Sorry, I'm not answering these yes or no..

Ashley Fisher
No, no, you're fine! I'm just used to everyone going Yes. By all means expand your answers. And you didn't find the way around to be easy to understand.

Amy
Yeah, I mean, it was okay. I don't know. I guess I didn't really look anything like the little gnome trail, I didn't know about it, but it was you know, it was happening there wasn't like, if I'd gone in and I'd seen like a big thing about it. I'd totally picked up a leaflet for that, but I didn't know what was happening until you had to tell me about it.

Ashley Fisher
And I only knew that because I look at every single piece of paper and flier that a museum puts out and I happened to grab one. Yeah, when I was there.,

Amy
If I'd known about it, because it [I like things like that] Yes. And also it is like a structure to it, I can be like oh, well, I've done- I've seen all of it you know? And it's just a cute fun thing to do.

Ashley Fisher
Do you think the map would have been helpful. Either handheld or on stands or?

Amy
Um, I think.. I didn't know like, that's the thing, if there was an actual map, I probably wouldn't have looked at it because I just would have been bored. I like talking a lot. Yeah, but something like that where like, it's like a trail or something like that. I definitely would look at it, as it would be more engaging, right.

Ashley Fisher
So a map that's more....

401

Amy
Yeah, something I can actually do yeah, like if I go off as well... So I know where I am on it, but then I forget which rooms I've been in so far. So obviously if I can mark it off, [but I wouldn't want to do that on a plain map] but then like, doing it as a trail you're doing that anyway. Yeah.

Ashley Fisher
Thinking about the shop was the signage in there easy to understand

Amy
Was there signage?

Ashley Fisher
I mean, there were some labels and there was a sign on the till that said, take these upstairs

Amy
Was there? I ignored that. and I looked at it and went Yes, that means here. I clearly what I mean clearly not Yeah, I don't know if that was me just not reading it but I..

Ashley Fisher
No it's actually a very common thing not just amongst my participants but amongst all visitors.

Amy
If it's a till – a till that's not in use, put like a sheet over it.

Ashley Fisher
Otherwise it just invites people to stand out there. Yeah. Was there enough space to move around the shop?

Amy
There was when I was the only one in there, I think it might be real difficult for us with people in there

Ashley Fisher
All right, so where the toilets easy to find

Amy
Noooooo

Ashley Fisher
where they clean

Amy
Yes

Ashley Fisher
was the floor clean.

Amy
So I didn't pay attention to it, which means it probably was yeah.

Ashley Fisher
It didn't stand out to you.

Amy
Yeah.

Ashley Fisher
Okay, thinking about the staff, the staff members treated any differently than another visitor.

Amy
I don't think so. The guy was pretty cool about me going and sitting although he didn't- I did notice that when I went and sat down, he didn't follow me. So he stayed on the other side of the room because the second time I went to go sit down. I said I'm just gonna go sit down and then he stayed standing there so I couldn't really hear him I kind of needed him to like, follow me. Yeah.

Ashley Fisher
Do you think that was because of you sitting down and then his I don't want to say awkwardness but his own patterns. Where is it because he threw off this pattern or would you think?

Amy
I don't know I think he probably just didn't think about it. Like he was in his flow. Yeah. And it didn't cross his mind with an issue

Ashley Fisher
[Were they able to answer your questions adequately?]

Amy
He answered my questions! specifically for health about like seats are- Even though the seats were annoying. But yeah, he answered all my questions

Ashley Fisher
clearly you were sitting in the correct seats otherwise they probably would feel...

Amy
yeah I mean it did check them and they didn't say anything on it so I just assumed it doesn't say anything, [it's okay].

Ashley Fisher
I think that's a fair assumption. Did you feel welcomed at the museum?

Amy
Yeah

Ashley Fisher
Thinking about to the museum as a whole – where the displays clear?

Amy
Yes. There wasn't actually a lot of like written information anywhere. I like I would have liked a little bit more. As I said, I liked the idea of that oddities trail. I enjoyed that a lot, but I only saw two of them. There was probably more but it weren't immediately obvious sure. But I think did like how they had two of them (the handheld interpretation boards) on there. Yeah. So I could take one.

Ashley Fisher
Were the fonts easy to read.

Amy
Yeah. Like it was just a pretty standard...

Ashley Fisher
was the colour contrast alright?

Amy
 Yeah but it was quite dark colours.

Ashley Fisher
It was sort of gray on gray.

Amy
Like it was fine when there was enough light. Yeah. But like if you got them in a pretty dark room, [it'd be difficult to read.]

Ashley Fisher
Yeah, yeah.

Amy
It's mostly didn't know where it was going. Yeah. I understand why they need to keep a dark. though. I just find it interesting in the drawing room when it was a choice, they said that they chosen to make it dark. Yeah, I thought that was interesting because it worked really well. But from an accessibility point of view

Ashley Fisher
it's a choice.

Amy

Yeah. I mean, I probably could to be fair I quite like things being a bit darker – not if I'm reading things obviously. Yeah, just I find it more calm and neutral. Yeah, interesting. But there's not that much to read in there, to be fair. Just the guy talking really. Yeah, so I'm guessing there it did kind of work.

Ashley Fisher

Yeah. There wasn't a whole lot that's dependent on reading which is you know, benefit of them not having signs anywhere.

Amy

Yeah. I liked having those personal boards in every room. When there's too much text, I'm just not... not gonna read it. Yes, no. So I liked that there was a person I could actually talk to.

Ashley Fisher

I find that interesting. Because with your anxiety is clearly not about talking to strangers

Amy

never has been okay. Yeah, as you probably figured by the amount of times I was like "hi!"

Ashley Fisher

I have similar personality. I'm totally okay going and asking for information and still have crippling anxiety.

Amy

Yeah, well, that's the thing. Like, I'm going to overthink everything I say, but I'm still gonna say it.

Ashley Fisher

Yes, exactly.

Amy

Which I think is the best to tackle it. I mean, it's not, I'd rather not do the overthinking, but you're gonna do it anyway.

Ashley Fisher

At least go through it with it. have a reason to be anxious. Was the volume for the videos at a decent level?

Amy

I mean, it was loud enough. It was just all wrong Yeah I did already watch well no I don't, but it was like it was like uncomfortable.

Ashley Fisher

I have had someone actually take the headphones off.

Amy
I was thinking about taking them off. and that was mostly just the mix of at all. It was the, like the it almost sounded like microphone feedback. Like the fuzziness of it was no fun to listen to and only have like, loud like steps just like come out and no it just was all the whole thing was so uncomfortable. I did think about taking off but also I wanted to know..

Ashley Fisher
one thing I will say that they do have captions on that video automatically.

Amy
Did you know, I didn't even notice that. I mean, I personally have perfect hearing. I haven't had it tested but I put captions on everything.

Ashley Fisher
I process things better by seeing rather than hearing.

Amy
Yeah,

Ashley Fisher
so I have to have captions on. Well, maybe this is an OCD thing. Just to make sure I don't miss anything.

Amy
Well, that's the thing. I didn't realize how much I was missing until I put the captions on. Exactly. And I was like, I mean making caption. I've not heard that. Like, I can, like, go back on the thing and I'd be like, there's no way I would ever have heard  that.

Ashley Fisher
Yeah.

Amy
I didn't realize how much I was missing out on TV shows? Yeah. And especially because I watch a lot of sci fi as well by quite often it's quite loud and fast. Like Doctor Who is a really bad example for he talks so quickly and goes through everything and I'm like, just put on the subtitles. She, she and I was specifically thinking about Peter Capaldi because of how difficult he was [to understand].

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Ashley Fisher
Alright, so we're the stories and the tales of the museum easy to understand.

Amy
Yeah, yeah. I found the Woman a bit difficult to follow. The one that- she was telling me about the portraits. But for some reason the brain just stopped working halfway through and she was telling me something. Yeah. And I wanted to listen to her, but my brain was just a bit more of a difficult time with that. Yeah. I don't know if it was just because I've had loads of

information at once. Yeah, like, I'm starting to feel a little bit tired now. Yeah. Yeah, yeah. But the ghost stories before. I could listen to that.

-

Ashley Fisher
What was the overall noise level?

Amy
Yeah, I thought it was okay. I don't like it when it's too quiet because I don't feel like I can say anything. But I don't like it when it's too noisy either but for my tastes,  I think it was okay there was enough people to have a little bit of a babble but it was alright. But the ticking clocks were a little bit annoying. They were fine when I was there for like a minute or so but if I... I don't think I could have sat in that room.

Ashley Fisher
were there some places that were too loud

Amy
I don't think so, I think the café might get quite loud because this is such an enclosed space but I didn't notice it.

Ashley Fisher
were there any places that were too quiet

Amy
I think the drawing room was on the side of it but I think because I was chatting to the guy wasn't too bad. Yeah. I think because there was someone there, at no point did it the feel like.... sometimes you go to these old houses and it feels like you have to like swaddle you up as you walk around, like the only sound is your footsteps and I hate that. Yeah.

Ashley Fisher
How was the lighting level.

Amy
And I quite liked it. I quite like things being a bit darker. I get a lot of headaches, I have a muscle problem in my eye, it's quite common thing it's called [????] And it's a thing that happens to most people, but it's like one of those things. It's only there when it's there, so like I wouldn't have a headache. You would have a headache today, you know what I mean? Some people are just more prone to it, you know, so it's not like technically a diagnosis because you can't diagnose Hey, right, you know what I mean? I'm just really susceptible to it. But it's where it's like, my eyes are pulling towards centre again, most. Most people do that. But sometimes when I like to try and pull it back a bit further and it called is like muscle ache, basically. And it's like basically just normal eyestrain. Most people will experience it at some point, but I'm just for some reason, really susceptible to it. So things like when somewhere's really bright, or really dark, I can get a headache from it. And the only thing that fixes is special glasses I've got because they're not made for sight, they're made for fixing the muscles I can only see up to about here [about 4 inches from her face] but

407

because they're like a really strong prescription that like, Mine isn't like mine at all. For the Yeah. So I can only really use it whenever I see a book like this.

Ashley Fisher
So that's not a pair of glasses that you would just carry around with you

Amy
No, and sometimes I do if I want to go away for a few days, but like there's no point in me putting my bag because I can't, like I can't see it. Yeah.

Ashley Fisher
So do you think any places were too light

Amy
No, I don't think so

Ashley Fisher
What about to dark?

Amy
I think the first room that I went in was too dark to read the thing. The drawing room was very dark. But I quite liked it. It would have been an issue with something to read.

Ashley Fisher
Right.

[discussion about tea and coffee]

So were there enough places to sit and or rest?

Amy
Yes, but they weren't labelled very well.

Ashley Fisher
You are the like I said, You're the first person that's actually notice where the places to sit are.

Amy
there is actually a lot. There is actually loads of places to sit they're just labelled so badly.

Ashley Fisher
Yeah, I very much agree. Especially when they literally put a red chair that you can't sit into next to a red chair that you can.

Amy

Yeah. And there was a lack of places for me to lean on. Quite often. If I'm talking to someone I don't want to have to go to the other side of the room to sit down. I just want to have like take the weight off of my legs just a little bit just or like rest my backpack on the tables, rest my shoulders a little bit less or just something

Ashley Fisher
very, very normal. Yeah.

Amy
There wasn't many places to do that. And the places I could do that I wasn't 100% sure if I can get there's a table in the middle of the room. Am I allowed to lean? Yeah, and those weren't as clear because they didn't have anything written on them.

Ashley Fisher
Yeah, they were quite [??] about which ones had labels and which ones didn't? Yeah,

Amy
yeah. So I didn't want to assume that the ones without labels were okay because there's the chairs it was obvious because they did have a lot of labels. The tables were a bit

Ashley Fisher
yeah. In that family room, I think the table was okay to sit at and lean on. There was another desk against the wall that didn't have a sign on it was clearly a desk that opens up, so tempted to go over to it and open it up.

Amy
There's quite a lot of signs saying what you can't do. There's not many signs saying you're allowed to do, like you're fine. You can lean on that table.

Ashley Fisher
negative reinforcement vs. positive reinforcement. So what was one good thing about museum in general?

Amy
The guides were really good. The guides.

Ashley Fisher
And one negative one bad thing about the museum just in general.

Amy
The thing that annoys me the most was the decorations on the banister. That was like such a... I don't know there's something about that where I was like someone is clearly not even... like hasn't even crossed their mind that that might be an issue. Like it hasn't even like

Ashley Fisher
that people actually use bannisters.

Amy
Yeah like they didn't even and it's completely unnecessary but we just have to put it a little
bit further over

Ashley Fisher
to make sure it's tied to the side Yeah. Yeah. So what is one good thing about accessibility
for the museum

Amy
I like the cards.

Ashley Fisher
And what's one bad thing about accessibility for the museum?

Amy
the adventure we had to go on to get to the toilets. And also because the door was really
heavy but it wasn't that bad at the moment the like, if I, for example, I caught open bottles,
the movements really difficult and like putting any kind of like where my wrist really hurt. So
they have been much heavier than that. I found this to be able to... I just have to like use my
elbows on here.

Ashley Fisher
Yeah, there was a very heavy door. Did any barriers jump out at you?

Amy
 Oh, yeah, just something that was noticed as well and I didn't know is because I checked
my profile because there's no signal in the toilets. Yeah. And which isn't a really an issue for
me but if you were someone who like fell over a lot or like passed out or whatever.

Ashley Fisher
Yes. And there weren't any like

Amy
Pull cords – yeah, like, like, I'm not expecting you to put a pull cord and every single toilet
but if you don't have signal-

Ashley Fisher
if you don't have signal.

Amy
Yeah, well, even just like a bell. Yeah. Just anything.

Ashley Fisher
Yeah, cuz you can't predict how often toilets are used, so someone could honestly be sitting
there for 20 minutes and if they're  sitting on the toilet having a heart attack...

Amy

Yeah, exactly. Like, hit the head and they're like bleeding out. No one's come in and checked it. Yeah, like and they can't call anyone you know?


Ashley Fisher
No, I didn't see any toilet check signs either for staff members.


Amy
Oh, no, I didn't see any. So it was pretty clean though. So did you like that been in quite often, but it did. Well, it wasn't the busiest days. Yeah, because I'm surprised it's a Sunday.


Ashley Fisher
I definitely expected it to busier. Did any barriers jumped out at you?


Amy
The main thing that I was like this isn't an issue for me but could be a major issue was how long it took to get to the toilets. And the fact that like you could only get from that far end of the museum and there was no signposts in the rest of the museum to where the that staircase was that you had to go down. Yeah.


Ashley Fisher
Were there any access tools that that you used? Either that the museum provided or that you had on you?


Amy
I don't know particularly, the main thing that I discovered was the fact that I wore my gloves all the way around. I liked you can pick up the things in the signs. I also use the railing and I wasn't sure, they didn't really... I mean i guess someone might have gone leave that there as an accessibility thing


Ashley Fisher
Could the museum have provided anything that would have been helpful?


Amy
I don't think necessarily providing anything just like changing a couple of things. I don't know like, the bannisters were a big one. Maybe not like crowding the spaces that you walk by the top and the bottom of the stairs, especially the second staircase from the Hall bit. And there are things like at the top of the stairs and there was also like windows which encouraged people to stop at the top of the stairs. I mean, we did Yeah. Which, You know, I felt it crowded in a little bit. Yeah. Yeah.


Ashley Fisher
And because there were stairs going down on one at the doors- on one of the walls basically and then steps down another one. It felt almost... not dangerous, but certainly not very secure. Yeah,


Amy
yeah.

Ashley Fisher
what should the museum design into the exhibition?

Amy
Um, I would have liked to know more about the trail that they did. Like maybe a sign or a leaflet about halfway through like, just a bit more because I really like the little gnome trail, it was really cute. I realise it's aimed at the kids but I would have enjoyed it.

Ashley Fisher
Not all things aimed at kids are only for kids. Okay, we're almost done. How did the staff make you feel?

Amy
Really welcomed, I think. Sometimes, when you talk to these people, they have a lot of enthusiasm, but they don't really feel like they care what you think about it. Do you know what I mean? So like blurting out information because they want to talk about it, because they want to. I felt like they genuinely were like, you know, I'm gonna ask you a question. I give you a little bit more information and then.. especially the guy in the Blue Room.

Ashley Fisher
Much more of a conversation than a lecture.

Amy
Yeah.

Ashley Fisher
Did you feel you were treated differently than any of the other visitors?

Amy
No, I don't think so. Okay, oh, sorry. I'm just going to add to that, though, I almost would have liked to. Again, mainly referring to the fact that I went to sit down and that guy like just stayed on the other side of the room. Like I almost wish that they would have gone. Oh, do you want to sit? But of course they wouldn't have known to have done that.

Ashley Fisher
Right.

Amy
I almost wish that they...

Ashley Fisher
When we were in the family portrait room. I noticed you leaning on the chair. Very easy thing for her to go. Oh by the way.

Amy
Yeah, yeah, yeah.

Ashley Fisher
It's just about noticing those things. Yeah. Just training people to notice. Yes. But anyway, do you think you would have been treated differently if you had a visible disability?

Amy
Yes. Well actually it's hard to know unless you go like...

Ashley Fisher
I've been keeping an eye out when you go around for anyone that does have any physical disabilities. There was one time we had someone who I think he had Down syndrome. And they were like, not bending over backwards for them very, very accommodating. They were very patient, and they were explaining everything that he had questions for. And they were very, very invested in making sure that this person had a good experience.

Amy
See, that's pretty good. I really like that. Yes. So they should do that for everyone. Yeah, exactly.

Ashley Fisher
And it's trying to find the right balance between giving everyone that really special individual attention and not overcrowding them when they wan...

Amy
see that's the thing. Like I feel like today was a day when they could have done that. Don't get me wrong. I didn't feel like I was like, getting brushed off or anything. I didn't feel like anyone was going above and beyond. Yeah, but today was definitely a day when they could have done that. Because there wasn't that many people about and I in quite a lot of rooms was the only person asking questions. And I think I was sort of being like, tell me about it like I want you to do this. Yeah, yeah, I'm not you know, you wouldn't be crowding me if you did

Ashley Fisher
Yeah. You were sending out very strong nonverbal signals that yes, please tell me about this.

Amy
Yeah, I want to know about it. Yeah. Yeah.

Ashley Fisher
I agree. Would you visit again?

Amy
Yeah, yeah. I'll bring my mum

Ashley Fisher
There you go. If you could tell the museum one more thing regarding accessibility of their site, what would it be?

Amy

Move the Christmas decorations. And maybe prop the bathroom door open

Ashley Fisher
Alright.

## 4.4. Follow-up Interview.

We met at a café in York on 19 November, 2019 to conduct this interview.

Ashley Fisher
So this is our last meeting. And as I was going back over our last Audio thing. I skipped a whole bunch of questions. So we didn't talk about specifically, some things with the blue drawing room. Go over those questions. So let's go over those real facts so thank you back to the blue drawing room where the displays clear and clean.

Amy
Yeah, yeah, I'm ready. Well, yeah, I'm mentally logged in my brain is like a an example of something I think was done well,

Ashley Fisher
excellence and were there any things to read in there?

Amy
So if the guide wasn't there, I don't think I would have been interested in it. I think I want to call in and be like, yeah, the displays Cool, cool because there wasn't any signs or anything. Not that I noticed I didn't. I wouldn't. Yeah.

Ashley Fisher
Not to say ha, you're wrong, but there was a stand of this handheld. behind the tree though it's a I don't think it's the best placement. But yeah. I just find that quite interesting.

Amy
Yeah, if I didn't see people probably

Ashley Fisher
Yeah, exactly.

Amy
I did take a picture of a tree everything.

No, it's totally fine. It proves the point that you really need to think about placement of everything.

Ashley Fisher
No, I just find that quite interesting. So I want to have all of the evidence just in case, something here. So where the stories and the tales of that particular room easy to understand.

414

**Amy**
Did you tell me anything specifically about that room?

**Ashley Fisher**
We talked, I think you guys talked about the lighting and how it was meant. Oh, tell me more about that one. Yes.

**Amy**
Only half paying attention to what you said. Yeah. Well, I mean, he didn't really say that much about the room itself. I mentioned that it was already started to mention the new star and he said that it was supposed to be so it was like a party for because it was meditating space for like, the thing he specifically said actors or entertainers that we like to entertain. So yeah, I guess I gave him a bit of a backstory. But I know he did also mention about the seating is all about the knocking. Oh, yeah. Yeah. And he told me that without prompting anything either like I yeah, I didn't say anything first. So yeah, I guess you did. Okay. You told me. But again, that was because he was that I probably wouldn't, because I didn't see it was the overall noise level.

**Ashley Fisher**
All right.

**Amy**
Yeah. I mean, it might be a bit quiet, but I was talking to someone so it wasn't that bad. I didn't notice it wasn't like, it wasn't like I feel like I have to keep my voice and didn't feel like you were disturbing anyone else. So having that conversation In some places you get it does feel like quiet. Yeah.

**Ashley Fisher**
How's the lighting? The lighting level?

**Amy**
I liked it. Yeah. I felt like you know, it's quite chill. Especially someone who was bosses it was lots of different smaller lights around the stars the light refracted my glasses, right It's really annoying. That's very fair. And possibly I should pay together bad your vertical involvement right here yeah I felt like it. I could have sat in that room and like read a book. I would really I mean, I may have needed a book like yeah, if I was in the corner, but it was quite relaxing I colleges. Yeah,

**Ashley Fisher**
Okay, were there enough places to sit and or rest in the intro? Yeah. Bye.

**Amy**
Yes, where I saw it was actually a window so and he didn't tell me not to. I think there was a question on it. So I think it was meant to be sound. But I don't think it was actually a seat.

**Ashley Fisher**
Yes.

Amy
So might have been a little bit easier than some of the other rooms because it was at least like the sofas and things that sorry, obviously couldn't sell. Yeah, because they were facing goods.

Ashley Fisher
Yeah, yeah. Again, they made it very obvious when you couldn't sell the loft as obvious as to what you could do. Yeah.

Amy
But to be fair, I don't know if I was supposed to say oh, no, you didn't tell me not to. That doesn't mean that.

Ashley Fisher
So how are you? Are you feeling? Did you have any, any problems the next day or anything like that?

Amy
I did have a weird dream sign.

Ashley Fisher
Okay,

Ashley Fisher
Okay. So one of the things that you talked a bit about was the, the garland that was wrapped on the banister.

Amy
Yes,

Ashley Fisher
Yeah. Is that still something that impacted your visits?

Amy
Um, I don't think I had a massive impact. shut down the stairs with these I didn't like really aching legs afterwards. Oh yeah, I was out of breath but that doesn't happen and that combination says so maybe you did have some maybe I did but it is something that bothered me specifically because I was like such an obvious oversight. Yeah, it's like an obvious like we haven't either it hasn't been closed our minds and this will be an issue Sure. Yeah.

Ashley Fisher
And in that case it might be not so much that it's physically a package or visit but maybe it was one of those little seating niggles that you're like, you can really like Yeah. Yeah.

Amy
But she likes to be

Amy

Yeah, I like the oddities in the house and moving pointed out to me. But I just appreciate that like quite often we get to do things where they'll be a little plot, I call it or like a little like label on display. And then the other side of the room or on request is like a large castle. But I don't need a large tech tomorrow. I just need one that I can take so I don't have to stand there. I don't have to punch over a sign right. I don't have to like and also felt like an anxiety. I don't want to stand in front of the sign. Read it. Yeah. I feel like I felt like brain fog that day or whatever it might give me a little bit longer to absorb the information. I don't want to be standing there taking the time. Other people might be trying to read it yet. Or my was Yeah. But the sign was there and it wasn't like it was just what that was like one top of the other and you can pick up on a new Yeah. Away from anybody else. Yeah. Yeah. And that wasn't my popsicle request or like go somewhere else to buy me just get back to me if I want if you do have to request them Do you tend to Are you okay? I don't I still read the big I'm like I'm not gonna I'm not gonna find out what? Yeah.

Ashley Fisher

Which disability of yours Do you think impacted the visit the most? like

Amy

okay, like pain and fatigue. But again is fatigue which which yeah the fatigue but yeah the ability to like I don't know like stand up in the middle like towards getting a win over Welcome to t he woman in the Porsche struggle to concentrate. Yeah. But she got me on a pretty good day. So

Ashley Fisher

that was one of my other questions. If we had gone on a bad day, how do you think it would have been different?

Amy

If we go on like a moderate to bad day, I wouldn't have spoken to any of the people. That's okay. I probably would have done the same, which I do with a lot of people when I go people to museums is I go to room. I want to appreciate it. But I will sit down and watch the other person. Got it? I'll say something like, I'm just gonna wait here. Tell me your favourite thing. You've seen someone I'll go see that or something like that? Because I've had, I don't know. wander around aimlessly, especially when it's just a bunch of cabinets. I'm like I this is overwhelming. I take some time. Yes, I'm on a really good I was just gonna say because we've already talked, we've already scheduled you're okay with it, I just like I'm going because I want to enjoy it, if going is going to cost me a lot of stress because I have to do a lot of things. Because once I go by day once given that there's nothing else I can do. And which means that I have to know that I can schedule a whole day off from work. Or like what I'm doing particularly badly I have to like do like two days so that I have to have the whole day beforehand to rest.

Ashley Fisher

Sure, yeah. And you said you would like you were likely to visit the museum.

Amy

Yeah, yes.

Ashley Fisher

Did this visit reminds you of any other museums you visited and good or bad?

Amy
nothing's coming to mind okay. It is quite similar to a lot of places I've been but I call

Ashley Fisher
that's fine.

Amy
Yeah, it wasn't like it wasn't like a standout like this is completely different to anything I've ever seen. Yeah, I'm fairly Yeah. Standard National Trust experience like this a strong new sort of house for my hero.

Ashley Fisher
Yeah.

Amy
I mean, it's similar to be mission some ways whether it's just like a task. Yeah.

Ashley Fisher
Actually. I'm thinking back on your best experience going to museums. Are there any stellar museum experiences that stand out in your head?

Amy
Yes, but not for this reason. That's okay. I want to hear him anyway. Good. I think about this all the time, the museum and Dublin, okay, whether you want to write about this, the way that they display the human remains in the museum is absolutely fantastic. And those like I did, and maybe realize how bad everybody else was doing. The way I want you were discussion. So, the good news is, they have this this room that was sort of talking about this like, just general like history, like the main typically dedicated thing, but then even the rooms there was like these, almost like, these very like, circular We came on the ground, there will be signs telling you like, this is what's in here. Absolutely information about them. And then you go in, and then there will be the court flight. Yeah, no signage, nothing. Just that. And then as you left there be more information. And I really, really like that because you will want where you don't get was the last time. Yeah. And it meant that they could keep the waters of a controlled climate. Yeah, they could limit the amount of people walking passive and you can also like, stop. And it wasn't the word like labelled like an accident. The information was there, but it was before and after. It wasn't like in a cabinet with a label.

Ashley Fisher
Do you think there are different expectations put on paying versus non paid

Amy
I don't think this If I was paying to get into a museum, I don't want it to be like, two selfish reasons. Right? Like, for me the main expectation is like the time that it's going to be. Okay. So you got something Yeah. Like if I paid to get in I wanted it to be was the hours that I spent finding that money? Yeah, you know what I mean? So like, this is just like if I if I say you six pounds, and it's six pounds again to me to like, without thinking about it. I want it to take at least our God. Like, I think it'd be Roman Baths museum. It's like to quit to get in. I

would happily pay to quit for that museum. Hey for quit for that no Sam quit to quit is it feels right yeah, that means Yeah, exactly. Because it's going to take you 15 minutes to get around it.

Ashley Fisher
So my last question is a personal question, but do you consider yourself disabled? I know, I know, this is a big question.

Amy
It depends on people that I sent the email I was like, Oh, yeah. Yeah. And it didn't even like, I didn't even question like, maybe I'm not disabled. In some situation. I'm like, yeah, according to the government, because I got to say, I think it has a lot to do with the fact that I don't have a proper diagnosis. Okay, I did have a proper diagnosis. I'm saying that. It's almost like whenever I say Do you consider yourself be disabled, I always pick the defined. Like it also depends on the day to save, like in in, you know, in the community forgot what I was trying to say well in the sense of like, I feel like something is disabled. Okay, as well as like an objective to describe me as a Fisher. However other days, I'm like I realized that this thing exists and still exists. Now. Yeah. Well, Joe be to say that.

Ashley Fisher
Yeah. So would you consider yourself a disabled person or a person with a disability which would you identify

Amy
But only because I feel like I feel like that was just a little time. I don't feel like I'm being disabled fighters. well. She was disabled person because she feels like she is like for me, because I'm gay. I consider that as part of my identity. Yeah. And like, I know, there's the whole like, Oh, I don't want people to just see me, but I want people to see me.

## 4.5. Follow-up Email.

I asked Amy for her experience with sunflower lanyards. Her email follows.

I do have a sunflower lanyard and I do wear it occasionally however my feelings about it have changed since the pandemic. Before the pandemic, I would wear it pretty much all the time. This was because it was a way of making my disability visible which has a number of advantages. It means people may be more accommodating, they may be more attentive to your needs and less likely to dismiss a request and members of the general public may do things such as give up a seat for you or allow you extra room. However, I have to admit that I didn't see many actual changes day-to-day. I would make sure to wear it in certain settings such as on a bus or train, as the staff are supposed to be trained to recognize it but I do not feel like it changed how I was treated. Most of the time people are accommodating and friendly but with or without a lanyard I would have to disclose a disability before I was able to get special accommodations.

However, I feel differently about it post-pandemic. During the pandemic, it became common knowledge that some people would not be able to wear a mask due to a hidden disability. As a way of supporting these people, it was shared on social media that wearing a sunflower lanyard may be a way of indicating to someone that you have a hidden disability. Unfortunate somewhere along the way this got confused and the message that was passed on to the general public was that if you wear a sunflower lanyard you do not have to wear a

mask. This resulted in two things, a lot of people suddenly knew what the sunflower lanyard was and therefore it wasn't a subtle indicator to trained staff anymore, and it also resulted in many people abusing this system because they didn't want to wear a mask and falsely believing a sunflower lanyard would allow them to get away with this. Suddenly, wearing a sunflower lanyard became political. I would often wear a sunflower lanyard specifically on days I knew I would also be wearing a mask, almost to make a point about how not all people with hidden disabilities have mask exemptions. Since then the lanyard has just become too loaded for me, it doesn't serve its original function anymore. I still own one and occasionally wear it but not as much as I used to. I try and make my disability more visible in other ways such as wearing a badge, and I find that more direct and effective than the sunflower lanyard.

Unfortunately, I think this is a case of a good thing being taken over by politics and it results in the meaning being lost. Part of me feels like I should continue to wear it and encourage others to do so as a form of reclaiming, but as the general public doesn't seem to be willing to have the conversation about what they are actually for it seems it wouldn't be very useful. They have also become very recognisable which means they, in part, no longer serve their original purpose of being discreet and likely will not again, at least not in the near future as they remain in the public consciousness.

# 5. Ellie.

Ellie is a woman with anxiety, chronic vestibular migraines, depression, and fibromyalgia.

## 5.1. Pre-visit Interview.

I met Ellie at her home to conduct this interview on 15 November, 2019.

Ashley Fisher
Just making sure. All right. So, as I mentioned before, we'll have a couple different meetings. So we'll have one now as talking about a pre visit stuff and then we're going to go to our museum and your case, in this case, at least is going to be treasurer's house, and I have a basic outline for how for what we'll do there. But by and large, I want you to lead the visit. Because I want to understand how your disability affects your enjoyment of museums and things like that. After the museum visit, we'll go straight to a café or a pub or something and have a chat about the experience. And then sometime hopefully next week, we'll have our last meeting and talk about the museum visit again, but also other museums you visited and how they compare. That's right. Yeah. Excellent. So I have a few questions for you. First and foremost, you mentioned that you have fibromyalgia, anxiety, depression. And was there something else? Yeah,

Ellie
chronic vestibular migraine.

Ashley Fisher
Okay. Yes, migraines that was there. Alright. So, I've done a little research on all of them, but go ahead. Tell me what they are because you're the expert on them. You're the one that has lived experience. Okay.

Ellie

So I'll start with the migraine, because that's one of the longest so that affects me and I have Like quite serious headaches, but also with a particular kind I get I struggle a lot with dizziness because it affects my inner ear as well so things like I got lots of symptoms to get with motion sickness so a lot of knowledge a lot of dizziness sometimes collapsing okay with that visual problems as well and then the Fibromyalgia is constant widespread pain, particularly my joints so for me it tends to tends to be worse in my knees so walking a walk with a with a stick, majority of the time and fatigue and brain fog so even when quite often even like simple tasks are really difficult because I just can't compute what I actually need to be doing? Yeah, I think those are the those are the main things for that. And then the sort of anxiety and depression sort of go hand in hand. In that I get very stressed out very easily. And it's difficult to... just trying to think how to phrase this. It stopped me from doing things quite a lot in terms of like, trying to get the momentum up to do things. Yes. So it's, it's quite draining in that way in. Even just like, simple stuff like doing washing up, it feels like kind of like a mental battle to actually get to the point of being able to do it. Yeah, that's so that's sort of a constant background thing, which is Yeah,

Ashley Fisher
I am on medication for anxiety, depression and OCD. And I also have iron deficiency anaemia. So I very much understand brain fog and the whole it takes a lot to do simple task if I brush my teeth and shower in the same day. That's a good day for me. Yes. So I really very much understand that battle. Excellent. And these are all conditions that you're born with. Is that correct? They just sort of highlight at different parts of your age in life.

Ellie
The fibro is a bit of a weird one because I've been told that it quite often starts with like, they described as a traumatic event, which for me was starting uni. Okay, so that was pretty much first time in first year. I suddenly got like, knocked back by that and like, okay, didn't So I couldn't get out of bed for days on end. Is this just what being a student is like and then realize that it's really not but the migraines been like pretty much as long as I can remember. Okay. And same with the same of the mental health I think but again aggravated by uni.

Ashley Fisher
Excellent. Um Yeah, so that's wonderful. Um, how do these things sort of impact your day to day lives? life? Yeah.

Ellie
So with just sort of on a very simple basis, I always have to carry a lot of stuff with me because I have, I'm on several different types of medication that I have with me at all times. And then I have to have water with me and I have to have my walking stick So my films have to be like lugging a tote bag around with all yeah like accessories and yeah but yeah just like simple day to day tasks like going to the shop like going having lectures I have to allot a lot more time because it's just physically exhausting for me and quite often I get back and I just have to like get straight into bed because it just takes up so much like.. Do you know the spoons theory.

Ashley Fisher
Yes yes yes it yes

Ellie
it takes up all my spoons yeah so. So there's that and then the migraine makes it quite difficult working with computers and things and I have a lot of external triggers like right like

some lights in shops, like I can't go into certain shops because it's Just an immediate migraine trigger Like that was, that was so severe when I was younger that I'd like to be taken out of school. Wow. Okay, and so that was Yeah, so that's quite a problem when I have to kind of plot where I go according, like, you know can I tolerate x y Zed at the moment. Yeah.

Ashley Fisher
What kind of lights Do you know?

Ellie
It tends to be like, fluorescent strip lighting isn't great. But also there are some shops and I don't know if it's to do with a type of bulb, but there's like a low level flickering that Yeah, yeah. Yeah. And yeah, and it's something that I don't know if other people are as aware of it, or if they can just kind of like shrug it off. But I'm like, incredibly sensitive to it to the point where I'll go into a shop and then immediately there I'm just kinda Yeah. Yeah.

-

Ashley Fisher
Wonderful, right. That's our practice. They're wonderful. Seem alright thinking aloud. Thank you. Wonderful. So now I have some questions about how you prepare for a trip. So do you use websites? How do you find out about a place that you're going to?

Ellie
normally I would if I'm not looking for like a specific Museum, I would just kind of be like, you know what, what is there to do in this area? And see like what museums are have a quick look around the website and that sorry. Yeah, have a quick look on their website and then just things like opening hours if there are any, like specific exhibitions on at the minute or event because I tend Well, a lot of the museum events, certainly where I am tend to be quite like child oriented ones so I might like see when the events are on so I might be able to avoid them so they're not as busy Yeah. Cuz it can be quite intense, especially if it's like a small museum. Yeah. Yeah, have a quick look about, like, how to get there. And just try and get a general impression. Like, from the website of what like what the feel of the museum's going to be like.

Ashley Fisher
Excellent. And that's all on the museum's website. Yes. And what information do you need? So obviously hours, what's going on how to get there feel of the museum? Is there any other information that you're looking for

Ellie
cost

Ashley Fisher
costs? Yes. Excellent. And do you use any accessibility tools like screen readers or colour overlays or anything like that?

Ellie

I do have a screen reader. I tend to use it more on like actual documents as opposed to websites because it does not respond very well to website

Ashley Fisher
that's the websites fault. Yeah.

Ellie
Tell ya I tend to I do I do try to use it but I might have to give up quite quickly with a lot of them because it's just easier to risk the like migraine or just have a quick look rather than wait for my screen reader to battle through the website. Okay.

Ashley Fisher
All right. And when you as you're getting ready, what sort of equipment or aids do you do you bring with you? You mentioned medication earlier. Yeah.

Ellie
So I will always have my painkillers, anti nausea medication with me. And I have to take my water as well because I've legal to set them with and I will take my walking stick as well. I've been using it or if it's like a really good day I'll just like, take it with me. Yeah. Yeah, I think I think that's it for equipment that I take with me, okay?

Ashley Fisher
Are there any eventualities that you plan for

Ellie
and I would usually take some kind of snack with me as well because particularly when I have a like migraine attack or a fibro flare up, I tend to like need food quite quickly. So I'll try and have something sort of sugary with me in terms of like if I do have an attack whilst I'm out, there's not really that much I can do about it aside from like, If I need to, like text somebody so I'll just make sure my phones close to hand.

Ashley Fisher
All right, and how much time does it normally take you to get everything ready? I'm

Ellie
probably only about 5-10 minutes because I tend to keep I keep my medication in my bag and I keep my stake in the same place. So it's, it's pretty much just go and collect everything

Ashley Fisher
pretty much organized ahead of time. And yeah, one of those daily routines that

Ellie
Yeah, cuz I mean, because I always have to take these things out with me when I go out regularly. So it's not Yeah, museum specific. Right.

Ashley Fisher
Excellent. So, pardon me, for the visit itself. We're just going to be doing what we've been calling a semi structured visit, which means that by and large will follow Your lead will go

where you want to go in the museum spend as much time as you like in them, whatever you want to do, I want this to be as normal a visit for you as possible. And that being said, there are a few points that I want to make sure we hit during our visit. Very basic points. They are visiting a particular exhibition. For treasures house, it's the sitting room, which I will make sure we get they're asking a staff member for help purchasing a small item from the shop, I have five pounds in cash, so you don't need to worry about paying for it. And visiting the toilets. Very, very simple things that most people do. Every single visit they do anyway, it's just so I have points of actual comparison between everybody. And then like I said after the museum or go to a nearby pub or something, have a drink or snack and do a bit of a debrief and a few questions and I want to do a visit audit with you which I sent. I believe I sent you already. Yeah. Basically we'll just go through a checklist and see how the museum's doing in certain areas like noise and light levels how easy things were to Read things like that. So does that make sense? Yeah, sounds excellent. And the visit itself can last 20 minutes if you want it to. It doesn't have to be, you know, hours and hours and hours. So don't feel pressured to stay for a really long time. It's just a normal visit for you. So all right, let me stop this.

## 5.2. Site Visit.

Our visit to Treasurer's House took place on the same day. The audio was recorded, but there was nothing relevant to transcribe.

## 5.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
Okay, we've gone through that. Now we're going to do our visit audit while we're waiting for our hot chocolate. Yes. So was it easy? So we went from your place to the museum by walking. So how well do you think those were? Things were signposted. And

Ellie
it's a bit hard for me to tell you this one because I walk past a sign for it all the time. So I have a background knowledge of where it was. Yeah. After we passed that like initial sign, it was easy to find. If I was coming from a centre view without any prior knowledge. I'm not sure I would have found it. I don't know that there's any I've never seen anything like to green metal signs that they have for like Barley Hall and things.

Ashley Fisher
Right and Was it easy to get from point A to point B?

Ellie
Yes

Ashley Fisher
Okay, so was it easy to find the museum from the street?

Ellie
Yeah.

Ashley Fisher
Was it easy to find the entrance.


Ellie
Yes.


Ashley Fisher
With the layout of the museum, easy to understand.


Ellie
Not really. I could have done that some more guidance as to if there was a particular direction that I can A couple of times especially when I went up the staircase in the grand hall where I got to the top they didn't know what to go to court Oh stretching off and I like wasn't sure which way to go even though all of them like led to the café it wasn't very clear from like the top of the stairs right?


Ashley Fisher
Yep. Excellent. And there was another group there. That's a bit confused as well. Yeah. So and the shop was the signage easy to understand.


Ellie
No. With the sign saying please be upstairs next. Yeah, set of stairs, but they weren't the stairs that you need to go to pay. Yeah. Which was quite confusing. And also wasn't a way of like, getting someone's attention. You're waiting there, which wasn't great. Yeah.


Ashley Fisher
Okay, was there enough space to move about?


Ellie
Yes.


Ashley Fisher
And was it easy to navigate the shop


Ellie
Yeah.


Ashley Fisher
Wonderful. Thank you. so was it easy to navigate shop them.


Ellie
Yeah.


Ashley Fisher
Were the toilets easy to find?

Ellie
Fairly

Ashley Fisher
Was the toilet clean?

Ellie
I could have been better. Okay.

Ashley Fisher
And was the floor clean?

Ellie
Again could have been better. Also, weirdly, it took me like five minutes to find the light switch.

Ashley Fisher
Oh really?

Ellie
Yeah, it's one of the things. It was a cord. But for some reason when I went back, it's because it's dark immediately when you go I don't know if that's just me being unobservant.

Ashley Fisher
I honestly haven't used their toilets yet. So I'm getting all this second hand experience. I'm waiting until we've done all the participants and then I'll go and see them. All right, the staff did the team members treat you any differently than another visitor?

Ellie
I don't think so

Ashley Fisher
Was the team member able to offer appropriate help when.. You talked to the woman up in the king's room about the ...

Ellie
Yeah, I think although the all the room guides were really helpful.

Ashley Fisher
Okay. Did you feel welcomed in the museum?

Ellie
Yes.

Ashley Fisher
Now thinking about the exhibits where the displays clear?

Ellie

um, I think once I got like, what's, what's out what they're doing in terms of like three different stories and stuff. It made sense. But it wasn't immediately clear it would have been maybe nice that been like a board saying like colour coded say all the green boards are about this. The purple ones are about this

Ashley Fisher

Were the fonts easy to read.

Ellie

Yes.

Ashley Fisher

Was the colour contrast good or appropriate?

Ellie

Yeah. Yeah.

Ashley Fisher

How was the volume for the videos?

Ellie

On the one in the Roman bit- really loud really loud. I had to take the headphones off because it

Ashley Fisher

I was wondering about that. Yeah.

Ellie

The only other one was music. Yeah, I was just gonna say,

Ashley Fisher

yeah. Okay. Were the stories and Tales of the experience, easy to read and understand.

Ellie

What do you define story or tale,

Ashley Fisher

I think in the way that they present the information, the stories and the narratives based on the handheld panels.

Ellie

Yeah, I think so. Yeah.

Ashley Fisher

Right. How was the overall noise level?

Ellie
It was fine. It was a little bit noisy initially in the first room, that we went into was the one. But I think it's just a big group of people.

Ashley Fisher
It was remarkably busy today, right? Yeah. I've never seen that many people in  the treasurer's house, so were some places too loud.

Ellie
The first [room] yeah

Ashley Fisher
were some places to quiet

Ellie
I don't. I've never thought a place in a museum was too quiet

Ashley Fisher
that was a very common response. How's the lighting level?

Ellie
Not good. That was probably the thing I struggled with most just because it changed so much. Right? And I understand obviously like flux levels and I need to get preserve textiles and things. So I understand that, but I just wish they had done it more consistently because it was quite jarring going from like natural light to artificial light to like, mixture. Yeah, and I like the blue drawing room was a real struggle

Ashley Fisher
going off that were some places to light.

Ellie
But yeah, that was that was too bright. It made me feel ill. Okay, just, I think just the intensity of it and everything else was so dark. Yeah.

Ashley Fisher
And was there any place that was too dark?

Ellie
weirdly, it was both

Ashley Fisher
Were there enough places to sit and or rest

Ellie

not in the downstairs? The upstairs was fine there were like quite a few different areas but I could really have done on the bench maybe in the Great Hall or something

Ashley Fisher
now thinking about the blue drawing room where the displays clear and clean

Ellie
I think they were they would have been clear if they've been enough like to see them. Yeah.

Ashley Fisher
Okay, and where the fonts easy to read?

Ellie
Yes

Ashley Fisher
and was the colour contrast

Ellie
Yeah

Ashley Fisher
The stories and tales of that exhibition in that room is easy to read and understand.

Ellie
Yeah.

Ashley Fisher
And how was the overall noise level?

Ellie
Um, yeah, I think noise level was fine.

Ashley Fisher
And the lighting level?

Ellie
Very bad.

Ashley Fisher
Right. And were there enough places to sit?

Ellie
No, I don't think there was anywhere to sit.

Unknown Speaker
Up to the audio? Yes.


Ashley Fisher
Physically How are you feeling after that?


Ellie
I'm feeling quite achy. And the thing because in museums like that, it's a lot of like, short walk then stand short walk then stand It puts quite a lot of pressure on my joints. Yeah. So by the end of it, I'm definitely ready to sit down for sure.


Ashley Fisher
Were there any rooms in particular that were difficult for your migraines or that you thought might have been a trigger for them?


Ellie
Blue drawing room again


Ashley Fisher
and again, that was the intensity


Ellie
Yeah


Ashley Fisher
So what was one good thing about the museum in general?


Ellie
I really liked the, the way they approached it because it is quite a difficult place to curate because you're trying to, like tell the stories of the objects but also, like weird way they've been put together. Yeah. And of the house itself. So I like that they have this like multi strand narrative going on. And I like that you could kind of because of the format of it, you can kind of pick and choose how much you wanted to, might engage with it. As opposed to having like big obtrusive signboards everywhere. It was quite nice to just be able to say, right, I want to read about this in this room. And that's it.


Ashley Fisher
Okay, and one bad thing about the museum in general.


Ellie
The main thing that stands out is just the lighting.


Ashley Fisher
Okay. This is really interesting because every single person across all the sites and all disabilities, single that lighting as like the biggest thing, and that's something I really didn't expect. So one good thing related to accessibility about the museum

**Ellie**

I'm not sure like accessibility specific. I like that- again, I don't know if they did this like intentionally but I liked that room upstairs. That was like a sort of like a quieter space. The little exhibition room. Sure. That felt like a nice, nice place to like decompress. I noticed as well, I had some like colouring in stuff was also probably a good place to play with children. Like, right. Sorry, I can't tell what I'm trying to say

**Ashley Fisher**

like, um, like a quiet room or a, like a sensory room or Yeah,

**Ellie**

yeah, I know you're trying to say but yeah, I don't know. I don't know how much of that was intentional or how much was just we have an exhibition space. But I'm like, I think it is a good a good space for that. Yeah.

**Ashley Fisher**

And one bad thing related to accessibility.

**Ellie**

I'm gonna go a little bit off script here and not say the light. Okay. It's a decoration on the bannisters Sure. It's just not it's not feasible and it does look really nice, but it's just not Yeah, it just doesn't work.

**Ashley Fisher**

But that there should be some compromise. has helped people upstairs.

**Ellie**

Yeah, I mean, even if you don't have what accessibility issues, it's just kind of a natural. You can go to grab a banister, you just get like a battery pack in your hand. Yeah.

**Ashley Fisher**

Does anyone any barriers jump out at you? Not necessarily related, just to your disability or just to you.

**Ellie**

I don't know what the options would be for a visually impaired person. Okay, cuz we went when we went anyways, we weren't offered an audio guide or anything. Yeah. So I don't know. Aside from that, like one video in the cellar. It seemed like there was basically one way of the information being presented and if that way didn't work for you then you were kinda stuck. And I think the other thing is just sort of, again, physical accessibility and I'm able to climb stairs and things on good days, but obviously that's a limit to how much you can do about that in a building.

**Ashley Fisher**

Were there any access tools you felt that they provided that you thought were helpful?

**Ellie**

I don't think they provided any access tools

Ashley Fisher
could there have been anything

Ellie
I would say some kind of audio element would be useful. Yeah, I think that's probably that's all I can think of that you could do really without like most structural changes.

Ashley Fisher
What should museum design into these exhibitions from the beginning, like font choice, colour schemes, multi sensory.

Ellie
I think multi sensory really important. I think getting a good balance between text and image I think they did it mostly on their information boards, but there was some of them that were like really text heavy. And it'd be nice to just make sure there's like a balance, so it's not too overwhelming. And the think, as well, maybe thinking about how people like move around the museum and think about maybe giving a bit more guidance about like, what you should go because again, I didn't really realize until we're coming back through that there was another staircase in the hall. Because, obviously, the hangings were in the way. Yeah, so that wasn't, it would have been nice to have maybe a little sign saying further galleries up here or something.

Ashley Fisher
Okay, did you bring or did you use anything that you personally supplied? So you brought you used your walking stick

Ellie
Yeah

Ashley Fisher
Okay, and how did the staff make you feel?

Ellie
Um.. The room guides were really nice and welcoming. And so were the people on the like, as you went in like the front desk. The person in the shop made me feel like a bit of a nuisance. And I understand it's difficult going between like being in the café and being in the gift shop, but yeah, just seemed quite impatient. And I felt like I was See I was a bit of an inconvenience.

Ashley Fisher
Okay. Do you feel you were treated any differently than other visitors?

Ellie
I don't think so

Ashley Fisher
[cleaned up a bit of a spill]

Let's go back to them. Did you feel you were treated differently than any other visitor?


Ellie
No


Ashley Fisher
Do you think you would have been treated differently if your disability was more visible?


Ellie
I'm not sure, based on the kind of interaction that I was having, because there was sort of more with the room guides and just learning about the room. Yeah, I'm not sure whether I would have been treated any differently. And that but possibly at the maybe the ticket desk, I might have been asked if I needed any help, or anything along those lines.


Ashley Fisher
Okay would you visit again?


Ellie
I think so. Yeah.


Ashley Fisher
It's okay to say no


Ellie
I think I would visit again when I was less brain foggy and able to take in the information boards a bit more


Ashley Fisher
if you could tell the museum one thing regarding accessibility of their site, what would it be?


Ellie
It would be taught something about the lighting. Yeah. Because it does make a really big difference and if especially from what you're saying if people with other disabilities as well upbringing off as well, it's quite possibly just a universal issue yeah needs addressing.


Ashley Fisher
It really does and it's always for different reasons. And one was because it interfered with their dyslexia so it's very difficult for them to be able to read in general and having little lights only exacerbated it. Another was an older person. So they I don't think that they had any visual difficulties, but they just had old tired eyes. Yeah.


Ellie
You know? Yeah. And especially with the amount that you read when you read in a museum, without really realizing it. Yeah. It can. It can get tiring very quickly.

Ashley Fisher
Oh, yeah, absolutely. Excellent. Alright, that's all I have for this one. Great. Okay. So, do you want to set the date for our next meeting? No, no, I'll do it now. And then we have it set. Yes.

## 5.4. Follow-up Interview.

We met at a café in York on 21 November, 2019 to conduct this interview.

Ashley Fisher
How are you doing?

Ellie
I'm doing okay. Thank you. Yeah, yeah, it's been a bit of a tiring week.

Ashley Fisher
But yeah, this has been very cold, which hasn't been hoping

Ellie
my phone dropped down to zero for the first time. Oh, my goodness.

Ashley Fisher
Yes. Super not fun. How did you feel the next day?

Ellie
And it really took it out with me that yesterday I was quite surprised. So I'm sort of normally if it's like a really big stately home, kind of like Castle Howard. Yeah. Kind of thing I expect to feel kind of drained afterwards, but because it was like a smaller museum. I didn't think it would have as much of an impact but I went to meet my, my sister for coffee afterwards. Yeah. And then I went home and just sort of crashed for a couple of hours like yeah, just by full on. Had to go for a nap. Yep. So, so yeah, it was it was physically quite demanding.

Ashley Fisher
Yeah. We will keep that in mind for our other trips. Okay, um, when we were talking last time lighting was big issue. Yeah. Still feel that way?

Ellie
Yeah, I think so. It's still a something that when I sort of think back to the visit, it's quite a prominent issue that was brought to mind. Yeah.

Ashley Fisher
Do you think the lighting or the lack of seating was more of a more of a problem for you?

Ellie
That's a difficult one. Umm.. I think probably the it's, it's difficult because the light- because it's sort of for two different conditions. Exactly. Yeah. I think probably the, the lighting because it's more of a thing that is going to have a long lasting impact. Because it's a migraine trigger, it's something that I might not necessarily realise. Sure at the time because it's kind of like an ambient issue. Yeah. If it was getting to a point where I was like, I can't sit

434

up anymore. I know that I could go and sit in the café or something. Yeah, the lighting is a bit harder to escape. Yeah. Thank you.

Ashley Fisher
Thank you. Okay. So then the lighting would have had the biggest impact?

Ellie
I think so. Yeah.

Ashley Fisher
Which of your various disabilities do you think had the biggest impact on the visit?

Ellie
I think probably the fibro, okay. Because that was just in terms of the physical aspect of like getting up and down stairs. And yeah, I find the kind of, I guess the museum walking pattern that you do like walk a little bit and stop and read a bit and walk a little, but weirdly seems to be like harder to deal with all it has more of an impact on how I feel. Yeah. And so even if, like, if I was walking solidly for like 20 minutes or something, it wouldn't have as big an impact of if I was like more than five minutes stopping for 10 which is a strange thing, but yet I just noticed

Ashley Fisher
that I had someone mentioned that they have to go, the rate that they go, they can't go faster. They can't go slow because it can be physically painful for them, right. Is it something like that?

Ellie
Yeah, it's I think I think it's kind of the movement you get used to used to like constant movement and you can kind of account for that. Whereas when you stop paying... I guess you like shifting weight and stuff without necessarily realising it. And then that can have I certainly feel as more of an impact in my like in my hips and knees after like museum visit then than regular walking.

Ashley Fisher
Interesting. Okay. And you really liked the handheld panels?

Ellie
Yes.

Ashley Fisher
I've got hot chocolate.

Ellie
Yes, I liked the I like the handheld panels. I think just size wise they were just that slightly awkward size that were slightly bigger than a A4 which I think it's just because you know, you used to holding something that's A4, it just felt a little bit awkward. Yeah. But in terms of like the design and the intent behind that. I really like them.

Ashley Fisher
How about the weight to them?

Ellie
Surprisingly heavy. Again, I don't know if it's the kind of organisation size that made that feel more prominent. But yeah, they felt they felt weirdly heavy for what they were.

Ashley Fisher
Yeah. Okay. And the decorations on the Banister?

Ellie
Yes, yeah. Yeah, just an issue. I mean, it's not completely like you could grab on to the decorations on the banister don't know how tightly that tied on and that could be a whole other thing. Yeah. So yeah, so that's that's definitely an issue.

Ashley Fisher
Do you... when you're doing research, do you check out accessibility guides or an accessibility page on their website?

Ellie
Um... I don't tend to know. And it's probably something that I should start doing. But I tend to kind of try to get an idea just from generally the website of what kind of a space is. OK, if it's something that I'm going to have, like significant issues with if, if it's like a really big site, but I suppose when I'm looking at things like entry fees and stuff, it normally comes up with a thing saying like, you know, accessible for wheelchair users on which I generally take as kind of a, you know, there should be ways around. Yeah, but I very rarely go specifically looking for accessibility information.

Ashley Fisher
Okay. And I believe that you said you would visit again.

Ellie
Yes.

Ashley Fisher
Still believe that?

Ellie
Yeah, I think so. The I've been thinking a lot actually about the tapestry room. Hmm that's kind of a place that stayed with me the most and I think I'd maybe like to go back and and have another look round and yeah and explore a bit more maybe – not at Christmas, when they don't have the kind of the lights and the decorations and things up.

Ashley Fisher
Did treasurer's house remind you of any other museums That you visited either good ways or bad ways or

Ellie

and it reminds me a little bit of Temple Newsom which I went to a couple of months ago. And I don't know if it's just because of, I think possibly because of the kind of mixture of different periods in there. because Temple Newsom, some like it's got some like Tudor rooms, and then some later rooms in it. And the kind of change between time periods reminded me about. Yeah, and then I guess just sort of the general like, stately home experience. Yeah. It come sort of, like some of them can kind of merge into each other about

Ashley Fisher
Yeah, you need to have something a bit unique to your site in order for it to really stand out if we're taking this trip on a bad day for your disability, whichever one you want to choose, would that have changed anything?

Ellie
I think it might have changed whether I went upstairs or not. Okay. I might have just stayed unexplored the ground floor instead.

Ashley Fisher
And this would have been during a fibro

Ellie
Yes during a fibro flare and then if I'd been if I've been having a bad migraine, I just wouldn't have gone into the blue drawing room room. Yeah. Just sort of the minute I saw those lights, I would just have gone somewhere else. Yeah. And yeah, depending on sort of how anxious I was feeling on the day as well might have altered how I interacted with the room guides.

Ashley Fisher
Okay.

Ellie
Cuz I'm.. would be sort of more inclined hang back and just and not not approach or ask questions. Yeah.

Ashley Fisher
How are you feeling in anxiety-wise on that day? And

Ellie
I was I wasn't too bad that day. I feel just a little bit like, just generally nervous about about the thing. But yeah, it was sort of a

Ashley Fisher
Sort of the normal expectation of nervousness. Yeah,

Ellie
you know, rather than a specific like anxiety kind of feeling.

Ashley Fisher
This question, I may ask you a few times since we're doing this a couple times. Okay. Do you consider yourself disabled?

Ellie

I do. It's taken quite a long time to get to the point where I consider myself today but I do. Okay.


Ashley Fisher

Do you prefer a being a... do you prefer identifying as a disabled person or a person with a disability


Ellie

Um, I don't really have a strong feeling either way. If I'm, if I'm talking about myself, I suppose I generally tend to say, you know, as someone with a disability rather than as a disabled person, but it's not something that I've really thought about that much.


Ashley Fisher

In a lot of the disability literature, there's lots and lots of debate as to whether we should be doing that.


Ellie

Yeah.


Ashley Fisher

And right now, the official stance is we should be going with disabled person, but every single participant I've asked has said, person with a disability. And I think there's a lot more nuance that needs to be invited into this. I find it really interesting. And it's, oh, it's been quite unequivocal too they're like, no, definitely a person with a disability. You're the first person that's given any kind of 'haven't really, really thought about it,' but so I find it really interesting. Yeah. And


Ellie

yes, I think it's such a personal thing. I never thought the mandated like, this is the this is the official way that people should be referred to but it's so personal.


Ashley Fisher

It really is. And you should absolutely follow what the person wants to identify as. Absolutely. It's just been a since I'm writing about disability, yeah. My gut instinct had been person with disabilities for my participants. And so that's what I had been writing and one of my thesis advisory panel members said, well, you shouldn't really be saying disabled person because that's, you know, the government stance that you're supposed to do officially and it just still didn't sit right. So I'm very glad that I have this so I can keep calling you guys people with disability. Yes. That's clearly what you prefer. Yeah. So that's all my questions. Okay. Do you have any questions? Or anything you just want to chat about


Ellie

not not specifically about the the treasurer's house I think except I suppose. I don't know if the if you can go into this on but like, if you've got much of an impression of like, whether the National Trust we're trying to do much in terms of improving accessibility,

Ashley Fisher

so I can actually answer that question. treasurers house specifically has been very interested in helping my research because they can't do a whole lot physically to the place which is fine. I understand that. But they want to improve accessibility in whatever other way that they can. Because their head of volunteers I believe it is. Her name is Trish. She's been my main contact. She's been amazing. She has worked with lots and lots and lots of disability groups throughout her entire lifetime. And so she's very keen on making things as accessible as possible. So one of the things was the handheld signs. The first time I went around with her and just spoke to some of the room guides, they said they really really liked them. They didn't like how heavy they were. Yeah. So I'm trying to subtly ask all of my participants how they feel about the weight of them. Okay. And, and, yeah, you and least two other people have both said it's heavy. So that's, that's one thing, certainly. And yeah, they're very, very eager to see what they can implement, because obviously, there's certain considerations and different things. But

Ellie

yeah, it's interesting to see kind of how, how differently I guess places like stately homes have to approach as opposed to museums where they've got more flexibility to like, do structural changes. Yeah,

Ashley Fisher

exactly. And all of my case study sites are grade two, or grade two star listed Buildings so there's not a whole lot of physical changes that they can necessarily do. Yeah. But I think that the outcome, my research will show that you don't need to have big giant changes. Just stick a couple extra chairs in. Yeah, think about your lighting a little bit more. Maybe make the fonts, you know, not so ridiculous, like little changes. That will help just everybody. Yeah, and it doesn't have to be a huge expensive undertaking either. So

Ellie

yeah, because it is just it's little things that can make such a huge difference. And even for, like, non... people, like visitors who don't have disabilities, I'm sure like, things like the lighting and making sure that fonts are legible. Like it keeps different for everyone.

Ashley Fisher

Exactly. I took a participant around Barley Hall. She had arthritis andshe mentioned the lighting because she wasn't able to step into rooms because it was so dark, and she couldn't really see where she was going. She didn't want to stumble on things like and stuff like that. Yeah, I was like, that makes complete sense. Lighting really is a key issue, even if you don't need it to read, or because you have a visual... visual impairment or anything like that. So yeah, tiny little changes, helps everybody almost like good design as accessible design.

Ellie
What a concept?

Ashley Fisher
I know! But yeah, and then one of my thesis advisory panel members is the equity officer for the National Trust. She is in charge of looking at their policies and helping to implement some of these different things. And she's been amazing. She's been really good. And she's been very, very supportive. So yes, the National Trust is actually quite keen on doing what they can.

Ellie
That's great.

Ashley Fisher
It might take a long time. Yeah. I'm sure there's lots and Lots of discussions that have to be done, especially if they're gonna change the lighting levels. But hopefully there will be practical change. Yeah. Even if it's as simple as putting little green stickers on the seats you can sit on. Yes. more obvious, you know? Yeah, things like that.

Ellie
because there is nothing more disheartening than when he finally spotted chair and then realise it's an antique cheair and can't sit on that one. Yeah.

Ashley Fisher
So yeah, so that's, that's the answer to that question. Yes. Yeah. In fact, all of the case study sites have been quite eager to take on board any Well, they say they're quite eager to take on board any, any results that I haven't see. Right. And that's also part of why I'm not just taking you guys around, but I'm also shadowing and sort of digging into the, the corporate culture of each of them to see how easy it is to change things. Yeah, and, and things like that. And then you know, pointedly asking okay well why is it so dark in that room? Is there any reason that you don't have an actual light in the pantry for example? Yeah, yeah, you know, so

Ellie
yeah, cuz I guess they're... because all of them they're all sort of within trusts or like larger bodies. Yeah, no, no them independence. Yeah.

Ashley Fisher
Yeah. So Abby House Museum is part of Leeds City Council. Barley Hall is obviously part of your group, treasures houses National Trust. So they all represent one site out of a group, but also quite different organisation types. Yeah. So we've got the big national charity and we've got a small local charity and we've also got the local council that's recognised. So interest.... it's going to be interesting to see how, how different things change,

Ellie
Although I was I'd be really interested to see the abbey museum because I was really impressed by the City Museum. In terms of I don't know what I don't know if you would call it sort of accessibility in the kind of in the same kind of sense, but in the way that they've designed their galleries in terms of having lots of different activities and things for people to do. So I think, especially if you're with children, and I think so I've got a little bit of experiences. My my mom used to work with adults with special educational needs. And in terms of like, different activities and different ways of getting the information across that will be accessible to everybody in some way, which, which I was really impressed by.

Ashley Fisher
Yeah. So that's really interesting.

Ellie
Yeah. So I'll be interested to see if that's  like, a curator at the City Museum. That's really passionate about that. Council wide thing that they're really thinking about, yeah,

Ashley Fisher
we're gonna have a lot of fun we go right Every house. Yeah, it is quite big. So I'll warn you ahead of time. It's a lot like the castle museum here and about half the size. Okay. It is on two floors. So yeah, it's about just that first wing of the castle museum with the Victorians street the Victorian room. It's about that size. Okay. Yeah. And they have Victorian street as well.

Ellie
Is it Kirkstall Abbey?

Ashley Fisher
Right. Okay, it's across the street from it. Yep. Always disappoints me mildly that there's nothing to do with the monastery there. No. Abbey house. But that's just me.

Ellie
Always looking for monks.

Ashley Fisher
Exactly. Everything should be about monks. But you know, I understand that not everybody's thing. So any other any other questions you have for me?

Ellie
I don't think so. No. Okay.

## 5.5. Follow-up Email.

I asked Ellie for her experience with sunflower lanyards. Her email follows.

So I normally only wear the sunflower lanyard in situations where I feel like I will need significant help (e.g. airports, train stations – which I haven't been going to over the past eighteen months) but I honestly don't know if I would wear one now because of the confusion around their use by people who are exempt from masks. I have complete sympathy with people who can't wear masks but sort of wish that there was another kind of lanyard they could use as I think people are much more aware of it now as just a mask exemption rather than also an indication of invisible disability! I'm also concerned by their co-option by some anti-vaccine campaigners/COVID deniers who are abusing the mask exemptions. I really feel like the meaning of the lanyard has changed so much over the past two years that it's not actually that useful for people with invisible disabilities any more.

# 6. James.

James is a man with fibromyalgia.

## 6.1. Pre-visit Interview.

I met James at a café in York to conduct this interview on 22 November, 2019.

Ashley Fisher
Excellent. Okay, so my script here might sound a bit silly, but I'm Ashley. I know, yeah, we've emailed a few times and you know, we actually know each other too. So before we get started, I want to go over a few things just to make sure we're all on the same page. My research is looking at accessibility for people with hidden disabilities and museum and heritage sites. And you've been asked to be a participant because you have a hidden disability. As such it will have three meetings one now about how you prepare for a trip one immediately after this will be go visit. treasures house and I have a basic outline for things will do there. But by and large, I want you to lead the visit because I want to see how you experience a museum. And then immediately after that, we'll go to a café or something and have a little chat and have some hot chocolate because it's cold outside and then a few days Later we'll meet up again and talk about museum visit again and also just a couple other things that make sense. Excellent. I have a copy of the information sheets and the consent form if you want to have a look at those things and then sign your soul over. Basically I'm not gonna sell your data.

James
But you will sell my soul apparently, yes. Which some completely fine with. Just so you know, there wasn't much one left. So

Ashley Fisher
Okay, so do you have any questions before we get started?

James
Okay.

Ashley Fisher
I have a few questions for you. You mentioned that you have fibromyalgia and I've done some research on it. But you're the expert. So can you explain it to me and how it impacts your life.

James
Everything hurt. No, no, no. That's as good as anything. Everything hurts. Okay, so knees, ankles. toes fingers, elbows, shoulders neck. Every everything hurts okay? There's also a side complication called Costochondritis that appears occasionally flares up with it, which means all of your tendons in your chest, inflame.

Ashley Fisher
That's really not good,

James
which means you can't move. It comes and goes, sometimes good. Sometimes are better than normal. Some days are okay. And then other days are horrendous. Today I'm on a sort of a medium day It has been horrendous but I've had a couple of days rest before this where I have on purpose done nothing because of other reasons. Daughter coming up today. Excellent. So I wanted to be fit and healthy for her. Yeah. So I've had a couple of days of just chilling on the sofa and watching on Netflix. Although not chill and Netflix, no. Just relaxing on the sofa and watching Netflix

Ashley Fisher

so um, so it truly impacts your daily life and you have to plan things out more would you say

James
yeah, I use the spoons method is excellence. So you start off with a number of spoons depending on how you feel in the morning and then grade your activities accordingly.

Ashley Fisher
Excellent. And you're pretty recently diagnosed with it.

James
I'd be about.... oo, a year, Id say. A year now. Yeah, go. So yeah, and work have been understanding. I've moved from being an interactive at the JORVIK Viking Centre to Barley Hall where I get to sit and do nothing all day and glare at people when they come in, as I then have to stop reading. [comment about remembering he's being recorded]

Ashley Fisher
I mean, if we're honest, this is meant to be publicly available, but the likelihood of anybody reading this....

James
but they've been very understanding and I've moved from an interactive through to Front of House at Barley Hall where I've been given a cushion and a special touchscreen pen.

Ashley Fisher
Oh, really?

James
To help me manage my symptoms. Excellent.

Ashley Fisher
Are there any things that you've changed in your life to sort of help manage the condition?

James
Yeah, I guess, lots. But just I don't know really I mean I've not really thought about it like that but I've changed the way I come into work and I just manage expectations I don't expect to do everything at once. I batch cook now rather than just cook a meal for just the day. Yeah. Yeah, just little things that just help. Yeah, having recently moved as well that does help. Another thing that I probably Yeah, my Alexis okay. So things like turning on light switches could hurt if you just press it on a  really bad day and press the light switch pain would just rocket through your body and you'll be useless for the next 20 minutes. Yeah, so I got a Wi Fi light bulbs and Alexa and now I just say Alexa light on Alexa light off. So I don't have to worry about turning on- managing that pain because now it's just some quiet voice control. Yeah, there are several of a Alexa things that I'm going to be doing over the next couple of years will help me do even more and managing over more. But... money.

Ashley Fisher
That's really cool.

James
Yeah. Yeah.


Ashley Fisher
Very cool that I hadn't even thought about that. Yeah. And before your diagnosis do you think it had a massive impact on your life?


James
yeah. Huge and I probably didn't even realise it. Yeah. I just thought it was age. And this is what happens when you get out you know, obviously you have no life experience of it until it hits you. But I did notice and work did notice that I was taking more and more more time off. That I would wake up in the morning in agonising pain I couldn't understand why I was in agonising pain. To be fair, I had been an agonising pain. For five or six years previously, but the problem with fibromyalgia is that you cannot, there is no test for it. Right. You have to eliminate everything else. Yeah. And, you know, that can include things like MS. So obviously, you have those five and six years of non stop tests and you know, waiting for appointments and before it was arthritis at one point and all sorts of things. They obviously added stress to my life because not knowing what was causing the pains was a big, big problem. So the diagnosis was a bit of a blessed relief, horrible to hear but a blessed relief.


Ashley Fisher
So at least you have


James
because then we could start working on working out what to do. Yeah. As I say work had noticed that I was having more and more time off. it all ended up cumulating once I've been diagnosed Talking to Jane Tinsley, and we arranged that I could have a couple of months, just off on full pay and everything on on full hours as well. So that was all good. Yeah. Again. So that's another thing work being understanding since then I know that that it's kind of employment law. It felt good at the time. Yeah. Because they could have easily have said quite very easily and quite understandably, sorry, the job is no longer suitable for your needs. And we cannot make any reasonable adjustments. Yeah, because the law says that they have to make reasonable adjustments, but if they can't, that's not what they can do. And I was really worried that as a Viking as an interactive, what reasonable adjustments can be made. I couldn't do caps on. I couldn't do caps off. I couldn't do pre show because I couldn't stand for too long. I couldn't do coins because I couldn't hold a hammer. I wasn't trusted to do pod because I might drop the objects because of the pain and I couldn't walk around I couldn't walk around galleries because being on the It's about time. So it was just like, gee, what reasonable adjustments can we make? Because I literally cannot do any other position apart from sit on the boat and go [phrase in Old Norse]. And that was it. So obviously, mentally I was really down because I was scared that I might lose my job. Yeah. Because of reasonable adjustments and how are they going to be possible? Yeah. So when the chance came up that they said, Look, we can offer you some Barley Hall and some JORVIK admission shifts. You're sat down, we can get you a nice cushion, we can get you a touchscreen pencil. You're not putting pressure on your fingers. Welcome environment. Yeah. Yeah. And I will say that to anyone who wants to listen, they could not have been, they have bent over backwards.


Ashley Fisher
Very, very glad to hear that. One of the things I'm doing my research, obviously, I'm going around the sites with participants, but also I'm shadowing at all my Case Study organisations

and seeing how they treat their employees in situations like this. And it's very, very comforting to hear

James
that I couldn't fault them. Yeah, they're always asking how I am. Chantelle wants to do a follow up on how it's going in the next couple of weeks, maybe months. Who knows? Communication that is an issue, but that is a completely separate thing. But yeah, so now health wise, controlling the mental health with it, controlling my physical health with it. They as a heritage company, again, you couldn't ask for more. Yeah.

Ashley Fisher
Wonderful. Okay, so let's talk about how you get ready for a trip to museum. Do you actually go to museums

James
occasionally, occasionally.

Ashley Fisher
And how do you get ready for it?

James
I make sure I'm up and okay to do it. Yeah. obvious instant. If the pain is too bad, obviously, you know any plans just go out the window and lay in bed all day and read a book. But, yeah, it depends. If it's a smallish Museum, it's not too bad on a half decent day, you know, you just sort of like just mentally prepare yourself that you're going to be on your feet. Yeah, you don't do too much before you're going to go out. If it's a big Museum, then you do nothing until you're going and you know it's going to be painful, but you're gonna go and enjoy it. And then you go home and when you collapse and curl up into a ball and die.

Ashley Fisher
That sounds about right. Yeah. Do you do any information research or anything like that beforehand, or you just

James
No, I like to be surprised.

Ashley Fisher
Okay.

James
And disability wise. I mean, within York, at least, you know which ones would be hard and which ones would be Yeah. You know, for example going to Richard III or Henry VII from those stairs. It's probably not the best of ideas on a bad pain day. Yeah. But, yeah, no, I mean, I just sort of take it and if I can't do it all and if the stairs look too much at the time, you just don't do that part.

Ashley Fisher
Yeah. Okay.

James

I mean, there is times when I've gone halfway random museum and gone. I can't I can't do it anymore thinking you're on a good day but and then you get there and then all of a sudden it snaps and you're just like, No, I want to go home and die. Yeah.


Ashley Fisher

When you're getting ready to go out, is there any specialist equipment or aids or anything like that, that you bring


James

on a really bad day I'll bring a stick. But then on a really bad day. I don't...


Ashley Fisher

You're probably not going to go out either. Yeah. Do you plan for eventualities or emergencies or anything like that?


James

Nah, not really. We got we got we got smartphones these days so if an emergency comes up you can pretty much find out what you need. Yeah. call anybody you need to say no


Ashley Fisher

So having a good support structure. Yeah. excellent. How much time would you say it takes to get everything ready to go?


James

Not long. Like actually physically getting my clothes on and yeah they can depends on depending on the day. I mean, if it's a really bad pain day when you sit in bed and you don't do nothing, yeah. On a half decent day, you know, takes me about 20 minutes to get my clothes on. Yeah. Which may seem like a long time for just slipping on a T shirt, pair of jeans and if that's what it takes, yes, that's roughly how long it took. Yes. Okay. I'm not up and out in like two and a half seconds. Yeah.


Ashley Fisher

Excellent. Alright, so those are the questions I have for our pre visit interview for the visit itself. We're going to be doing what we call a semi structured visit. where basically by and large I'm just going to follow your lead we'll go where you want to last as long as you want to. It can last last five minutes if you want to, I really don't care. We're just going to make sure we hit a few points. One is making sure we visit a particular room. It's the blue drawing room. I will let you know when we get there. Another is asking a member of staff for help or asking questions, something like that. And one is purchasing a small item from the shop. I have five pounds with me so Don't worry about it, knock yourself out, and we're going to visit the toilets. So all fairly basic things that people look. Yeah, very much not want to visit right? And then after the visit will go and have snack or drink or something nearby and we'll go through a couple more questions and everything makes sense. Yep. Fantastic.

## 6.2. Site Visit.

Our visit to Treasurer's House took place on the same day.

Staff member
So as you go around, do take photos, there's information boards in the corner


James
I might disagree with the whole principle of ropes. But it does give you a flow. So as someone who's going to struggle, I'm going to struggle to get ready. And again, you feel like you want to see it all.


James
This handrail, so there's nothing to grab and hold on to. So if you do suffer from fibro, like me, they've blocked off the handrails. That's bad.


Ashley Fisher
Yes. You're actually the third participant to point that out.,


James
And that's pretty horrendous, really.


Ashley Fisher
and and you can tell that they don't have to be like here for example


James
It could have easily gone over the top rather than the actual handrail. So that's bad.



## 6.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.


Ashley Fisher
How was it getting to the museum?


James
Well, fine, as I said. On the thing, disabled access was not clearly marked, which I would have preferred to have taken rather than steps. Yeah, I mean fine. Yeah.


Ashley Fisher
If you were travelling to the treasurer's house from your flat, how would you have gone about it?


James
Bus


Ashley Fisher
bus

James
which would stop by Stonebow and then walk.

Ashley Fisher
Okay, so let's think about the museum in general. Was it easy to find the museum from the street?

James
from the street that it's on, yes.

Ashley Fisher
Yes.

James
But in general, no, it's a bit tricky to find it. Yes. No, real clear signage is a bit like Barley Hall. You don't know it's there until you're there.

Ashley Fisher
Yeah, yeah. Was it easy to find the entrance?

James
Well, that paths kinda led you there.

Ashley Fisher
And did you find the layout of the museum easy to understand?

James
No, not at all.

Ashley Fisher
Like we were saying there wasn't really a flow to it. And there were multiple points where you're like, have you been here before? Yeah.

James
Yeah, I got confused as to whether,

Ashley Fisher
yeah, alright, so thinking about the shop in particular, was a signage, easy to understand

James
Yeah, basically.

Ashley Fisher
I mean, there was a sign on the register that said pay for food and drink here. And the purchases upstairs.

James
Yeah. Which is very weird. Weird. Yeah.

Ashley Fisher
Was there enough space to move around the shop?

James
Yeah. I mean, it wasn't busy. So yeah.

Ashley Fisher
Was it easy to navigate the shop?

James
Yeah, well it was just one room. And there was nothing really on its way. Yeah.

Ashley Fisher
Very open. Yeah. That's not the page I want to turn. So thinking about the toilets now, were they easy to find?

James
They were. Yeah, well, sort of. I mean, that's just my lack of general directions.

Ashley Fisher
But there were a few signs here and there, were they clean

James
Yep

Ashley Fisher
where the floors clean.

James
Sorry, no, no.

Ashley Fisher
Okay. Excellent. obviously haven't been inside the gents, so I don't know. Thinking about the staff. Did team members treat you any differently than another visitor?

James
Don't think so.

Ashley Fisher
Okay. Was the team member able to offer help when asked?

James

One of them did say are you okay there, be careful. So I'd go with Yes. Okay. Yeah. It was a woman who was talking to us in one of the bedrooms and talking to us about the tortoiseshell.

Ashley Fisher
She was very nice. Yeah.

James
She said are you alright there. Be careful. Yeah.

Ashley Fisher
That's very nice. Um, did you feel welcomed at the museum?

James
Yeah.

Ashley Fisher
Not like, other museums that shall remain nameless. The exhibits in general were the displays clear.

James
I mean, I didn't read too much of the displays as you know. I'd prefer to talk to the Yeah, the volunteers. Okay.

Ashley Fisher
But it was easy to see like the objects and that?

James
Yeah

Ashley Fisher
we didn't listen to any video.

James
We did

Ashley Fisher
we What?

James
We watched that video?

Ashley Fisher
Yeah. So how would you say the sound level was for the video?

James

I mean, I think it was just video wasn't audio.

Ashley Fisher
There was a little bit of music in the back Yeah.

James
Sound Level was fine for me

Ashley Fisher
not very memorable then know. were the stories and tales. [drinks arrive] Were the stories and Tales of the experience easy to understand.

James
Yeah

Ashley Fisher
I think they did a good job connecting rooms between the guides as well. how is the overall noise level

James
It was fine

Ashley Fisher
any places that were too loud.

James
No

Ashley Fisher
Any places that were too quiet?

James
No, nothing. It was nice.

Ashley Fisher
What about the lighting levels?

James
bit low. But understandable at the same time.

Ashley Fisher
Yeah. Were there any places that were overall too light?

James
No, no, I would say I'm generally it was just a bit too dark.

Ashley Fisher
Okay. Were there any places that you think were too dark?

James
With the room which, again, that same lady showed us the tortoiseshell she literally had to get a torch out to show us certain things.

Ashley Fisher
Were there enough places to sit and over rest?

James
On the whole? Yes, there were a couple of rooms that didn't have a chair where you could sit, or at least I could see. Yeah. The guides were perfectly happy for you to sit on the ones that you could

Ashley Fisher
Yes. thinking specifically to the blue drawing room, which was the one with the big giant fireplace and the Christmas tree. Let's think about that specific room were the displays and everything clear and easy to see.

James
Yeah

Ashley Fisher
Okay. Where the stories and tales in that particular room easy to understand.

James
Yeah

Ashley Fisher
How was the noise level again?

James
Fine,

Ashley Fisher
and the lighting

James
again, you know, a bit on the dark side, but you know, I understand why it has to be that dim.

Ashley Fisher
yeah. And were there enough places to sit or rest in that room.

James
I can't remember.

Ashley Fisher
Give that a no then

James
I would say on a busy day because obviously we're out of season. Yeah. But I would say on a busy day in general that will be because of the sort of attraction that would attract the older person who may need to sit down a bit more. Yeah. So in general, I would say there wasn't enough on a busy day. you know, even though I've got a disability, you would feel wrong taking that seat. If that makes sense, but that's just me. To sum up in general. When I think about what a busy day I would say that that probably wouldn't be enough seats. Okay.

Ashley Fisher
So what's, what was your favourite thing about the museum in general

James
I quite like the volunteers to be honest. Yes, they were chatting and engaging, which is nice.

Ashley Fisher
Yeah.

James
It does make a change,

Ashley Fisher
it does really makes a difference.

James
but I say the same thing at JORVIK, I think your experience of your visit vastly depends on who's working. Yes.

Ashley Fisher
In sites where there are quite a lot of people stationed around employees and volunteers and such, it really does make a difference as to who's there

James
And I won't mention any names, but they're both gone now. But there were a couple of people there who didn't want to talk to anybody,

Ashley Fisher
which is kind of the opposite of your job description.

James
Little bit. So, you know, like everywhere else, you know, I mean, that can be volunteers that they have that don't engage. Yeah, yeah. So maybe just got lucky. But yeah, all the volunteers were very straight on it. Yeah.

**Ashley Fisher**
I will say that like the fourth or fifth time I've gone around, every time they've been brilliant. So I can't think of a single one that I was like. Yeah,

**James**
yeah. Yeah. All very good.

**Ashley Fisher**
What was your least favourite thing about the museum in general?

**James**
The lack of being able to hold on to the handrails. It's a big thing. No, it is. Yeah. If you put things that you can hold on to. Yeah. Going up to quite a lot of stairs. Yeah, I mean, at that point, I instantly had to sit down.

**Ashley Fisher**
Yeah, yeah. I'm laughing because you're the second person that that's their Least favourite thing about the museum. It's a big thing, actually. And

**James**
then you might want to hold on to the going upstairs here.

**Ashley Fisher**
Yeah, exactly. And it's clearly something that Wasn't thought about. It needed. Two seconds.

**James**
It looked pretty, but it was completely impractical.

**Ashley Fisher**
One good thing about accessibility related to the museum.

**James**
Well it was flat, It was quite flat, no trip hazards.

**Ashley Fisher**
And one bad thing related to site.

**James**
The stairs. I mean, you can't expect there to be stellar stair lifts. You can't expect that to be lifts. Yes. So they don't count because you're visiting that type of building. It's like coming to Barley Hall, or one of the medieval sites you know, I'm saying well, why isn't that lift? Well, because it's a 700-year-old building.

**Ashley Fisher**
Because there can't be

James
Yeah, so the handrails

Ashley Fisher
did any barriers jumped out at you?

James
Okay, the handrail was such a bad idea. Yeah. on accessibility issues. It was just wrong on every level. Yeah.

Ashley Fisher
Do you think the museum could have provided anything that would have helped you go around

James
those little seats that we discussed that you saw in the shop?

Ashley Fisher
What should the museum design into their exhibition from the very beginning

James
more handrails, so more sort of things that you can just pull- even on only two or three steps. It may not seem like anything to them,

Ashley Fisher
but that makes a big difference.

James
It makes a big difference. So just something to hold on to you as you go up the steps.

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Ashley Fisher
Back to the staff. How did they make you feel?

James
Welcome. very welcome.

Ashley Fisher
And do you think you would have been treated differently if your disability had been visible, or more visible

James
Probably. Yes. Yeah.

Ashley Fisher

How so do you think?

James
I don't know. I would just, you would feel, or you'd hope at least that they'd be like, if you need to sit, take one, that type of things so so just because you haven't – because of the hidden disabilities. They think obviously immediately there's nothing wrong with you. Until ou say, there's something wrong with me. And do you mind if I take this seat? Yeah, okay. But I feel that if we did have a physical- walking around with a stick, and they would say, Well, do you feel free to take a seat

Ashley Fisher
If you could tell the museum one thing regarding the accessibility of their site, what would it be?

James
Guess.

Ashley Fisher
Is it going to be the handrails?

James
Yes! Funny, that.

Ashley Fisher
Shocking. But see, these are all small. It's a very small change. And it doesn't have that much impact. It's not that expensive to do. But just make sure that you tie it on differently. Yeah. That is hopefully the point of all of this research that it's the Little things that make a big difference. I mean, yeah. Excellent. So for next time, just think about other visits to the museum. The museums you've worked at too. And we'll just have a chat we can meet at a café or a pub or dig again, whichever you prefer. Whatever.

## 6.4. Follow-up Interview.

We met at a café in York on 25 November, 2019 to conduct this interview.

Ashley Fisher
Right. So, hello. Hello again. How are you? I'm good, good. So we're just going to do a quick recap of our visit. Too much went on and get ready. So how are you feeling the next day?

James
Yeah, two weeks ago. That was a feeling the next day two weeks ago. Yeah.O kay. Yeah. But yeah.

Ashley Fisher
Would you say it's more than normal? Or sort of what was expected after a day? What was expected of this like?

James

456

Yeah, okay. Yeah, I was fully prepped for

Ashley Fisher
I sent you that photo that they just did the Yes. I know. I was looking back through the notes and that was like your biggest problem.

James
Someone must have told him

Ashley Fisher
must have Yes. Oh, yeah. So now that that has been taken care of

James
everything else was fine – apart from probably in the summer when they wouldn't been enough chairs.

Ashley Fisher
Sure. Okay.

James
For anyone with problems to sit down, yeah. You know, one chair in a room. All it takes is two or three people wouldn't ability issues. Yeah. That ran at roughly the same time and exactly

Ashley Fisher
Right. I can't remember if I asked you, would you visit the museum again?

James
I mean, if it was my sort of thing. Yes. Okay. Yeah. It's a nice building, but it's not really your it's it's not my sort of period. Yeah. So I enjoyed the most right. I feel Yeah.

Ashley Fisher
Did this. Did the treasurer's house remind you of any other museums? You visited

James
every single National Trust property on the planet?

Ashley Fisher
Yeah. So pretty standard then.

James
Yeah. Okay. Yeah, they have a they have a, they have a tick box list and they adhere to it and read properties. Yeah.

Ashley Fisher

Thank you back. Are there any stellar museum experiences that stand out in your mind when it comes to accessibility?


James
I'm gonna be honest: JORVIK.


Ashley Fisher
Yeah. Good.


James
Sing our praises. Just very good. Awesome. The latest access I mean, yes, can only have one wheelchair user at the time, but all the staff are fully trained to handle people with visual impairments any well any impairment at all. Yeah, they've got lovely chairs that you can take around and sit on. There isn't quite another museum like I mean, the chocolate story is very, very good as well. They've always got the chance that you can sit back draggable chairs you can't take them wherever you need. Yeah, front though the fixtures for our Yeah. So yeah, I mean, honestly, I mean without, you know, blowing our own trumpet your week does very, very well with that. So yeah, I think so too.


Ashley Fisher
Do you think there are different expectations put on paying versus non paying museums?


James
Yes, I think paying museums, there's an expectation is that you have to go above and beyond almost. But it should be outstanding because you're paying for the museum. On a personal level, I don't agree with non paying museums because the people who work there deserve to be paid. Yeah. Now I know for example, the railway museum. They stopped getting paid. Yeah, that's all from charitable donations. Yeah, rather than anything else. As far as I'm aware, I don't know the intricacies But no, I I think museums to keep up to date with technologies and accessibility needs and everything they should all be paid for museums rather than having to rely on anything else. Yeah. Yeah. Because it's the only guaranteed way of getting an income. Yeah.


Ashley Fisher
If we had taken this trip on a bad day, would it have changed anything? I


James
wouldn't have ended up with on the stairs.


Ashley Fisher
Okay. Yeah.


James
Especially with those handrail problems but even in general, I wouldn't have been able to download them stairs. Yeah.


Ashley Fisher
There's a lot of stairs in there. There is an awful lot of stairs.

**James**

So yeah, there's no there's no other way of getting around. Now I understand that it's a historic moment when you come in cetera, but maybe a challenge would have been in the family thing or some. You can get these things. I don't know. There should be ways around it. Yeah.

**Ashley Fisher**

One thing that they do offer is a tablet that has a photo guys, the different rooms that you would be able to see. How do you think that would? Would it

**James**

be? Okay, we do, do it. We don't do it here [at Barley Hall] actually. We used to do it here. Don't have a tablet. I think virtual reality would be a better way of doing it. Okay? Because it's more immersive whereas tablet is just photos. You could look at them online. Yeah. But some sort of interactive way of being able to explore would be a better, better means. Yeah.

**Ashley Fisher**

So this is quite a personal question. Do you consider yourself disabled?

**James**

Slowly, slowly?

**Ashley Fisher**

Yeah. Do you prefer a disabled person or a person with a disability

**James**

haven't gotten that far.

# 7. Jessica.

Jessica is a woman with dyslexia and Irlen syndrome.

## 7.1. Pre-visit Interview.

I met Jessica at her home to conduct this interview on 22 October, 2019.

**Ashley Fisher**

So my research is looking at accessibility for people with hidden disabilities in museums and heritage sites. And you've been asked to be a participant because you have hidden disability, as I mentioned, will have three meetings one now so I can learn how you prepare for a trip one later today afterwards, where we go to the museum. In your case, it's going to be treasurer's house here in York, and I'll have a basic outline of things for us to do. But by and large, I want you to lead the visit so I can understand how your disability might affect your experience after the museum will go to a café or a pub or something and have a chat about the experience as a whole. And then a few days from now we'll have our last meeting, or we'll talk about the museum visit that we took together. Yeah. And also about other museums that you've been to and how they compare. Yeah, that's all right.

Jessica
Yep. Excellent.

Ashley Fisher
That's great. Now I have a few questions for you. Yep. And these are bit personal. So you're free to say no, you don't want to answer them at any time. But you mentioned that you have dyslexia and Erlen's Yes, that correct?

Jessica
Correct.

Ashley Fisher
All right. I've done a little research on them. Yeah, you're the expert. So can you explain them to me.

Jessica
And so with my learning difficulty and dyslexia, it basically means that I... my brain works in a different way. So I kind of learned in different way to kind of what you normally would be taught in school and stuff. And so I particularly struggle with spelling and kind of reading and stuff like that and being able to kind of find the difference between different types of words and stuff like that. It's like they're and there like a different type two spellings and stuff. And then with Erlen's syndrome, and it's a light sensitivity and disability. And so for example, if there's really harsh lighting, or if there's lots of like, you know, writing on a page like this, and I find it quite hard to read it because my brain is kind of working really hard. And that's when I kind of started to get a bit tired and a bit stressed and a bit frustrated. And so I do have a colored overlay. And, and I when I kind of went through my disability, training and stuff like that, once I was diagnosed, I kind of got lots of software and Stuff like that on my computer. And so it will do it. It'll kind of read websites out loud to me or even PDFs and stuff like that. It's really cool. Like, yeah, the stuff that it can do. So it kind of, so instead of having to kind of just sit there and read, I can just have it read to me. And basically when I'm was like proofreading in my work and stuff like that, because I could read but you remember 1000 times I'm not seeing any spelling mistakes, that soon it's as it's being read aloud to me, I can easily kind of point out an "I've used "wrong spelling there," or "I've misspelled that," or "that's probably when I could use a new sentence or a new paragraph" or stuff like that. So yeah, that's basically my disability in a nutshell.

Ashley Fisher
Excellent. And because these are both types of neurodivergency, you're born with them. Is that correct? Yes,

Jessica
exactly. So it was really weird because I didn't get diagnosed until last year. Yeah. Um, so you know, even though I've lived a bit, you know, the whole of my life. It was until I got diagnosed where I was probably you're probably able to kind of see like, okay, you know, it's not because I'm stupid. Yeah because I generally have a disability and I just need some extra tools to do for me to be able to kind of you know, read and kind of excel in studying and stuff like that. So it was kind of one of those things where it was quite sad when I was first diagnosed I thought well obviously if I'm got disability, then I can't be in you know, I can't study. Then it was a bit like, Well, no, actually, it's quite a relief because it means that because I was was stuck, I was just stupid and just needed to work harder. And actually, that was not not the case. Oh,

460

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Ashley Fisher
5All right, so now when you prepare for a trip, I want you to walk me through what you do. What do you research anything ahead of time? Do you look for websites? Do you look at TripAdvisor, anything like that? What do you do to prepare for it?

Jessica
So the thing is, for next I was obviously so on the question. As I was thinking about that, it's very hard to because obviously having studied museums and being generally interested in museums, it's quite hard to kind of take it apart, like what I do my disability and what I do, because I'm interested in in museums and how they work and how they're set up and stuff. But I think in in general, I do kind of definitely do a little bit of research about the museum, not the actual museum itself, but the actual history and content behind it because because I do kind of learn in my own time and in my own way, I do find it quite nice to have that basic standing before I go. So then when I am kind of reading the materials there, I already understand a little bit

Ashley Fisher
Sure,

Jessica
just because I'm a little bit scared that because it does take me sometimes a little bit longer to fully grasp concepts and stuff. And if I'm not in my own comfortable space and able to use my own personal tools like my coloured overlay or my laptop and stuff, that I'm scared that I'm not really gonna be able to grasp the comments like the the actual concept of the history of stuff in the background. So I do always kind of like to do a little bit of background research mainly using videos and stuff. And just because I do enjoy kind of learning the kind of via audio and stuff like that, rather than then reading is what I've noticed I learn better that way to be able to actually grasp what's being said. So I do to kind of go on YouTube, or I might find a podcast or a documentary or something like that. And that's kind of how I find I I enjoy learning more that way. And I do use the see if they have any audio guides. So I do kind of research about Museum in terms of having the audio guides if there's an extra charge for it or anything like that, because if there is like a free audio guide, I do tend to want to use it better because I know that I will learn better around the museum rather than just stood there and reading but if there's usually an extra charge, then I do kind of make that decision. Whether it's Hey, am I going to take the audio guide on my not going to do a guide kind of thing because sometimes I like 20 pounds, but normally guys like I'm not gonna pay that I used to do look at TripAdvisor for kind of when the busiest times are. And because I do prefer to go when it's a bit quiet so I'm not feeling as bad if I'm stood right in front of the text panel, kind of because if it's quite hard to, to read because of the colors of the text panel or the harsh lighting, yeah, I do have to go quite close to be able to kind of read it and stuff like that. If it's really busy that I'm not going to want to do that because I feel quite awkward and quite pressured. And so do kind of kind of see what's the best times to go. So I know if it's going to be quiet or not. So I can kind of prepare myself okay, how much am I going to be able to kind of learn and how long am I going to spend in museum dependent on how busy it actually is going to be and I think that's kind of the The main things I do like before I do go mainly to see if there's audio guides or if there's any sentiments you can tell by the pictures that they have any headset so like stuff like that actually in the exhibitions themselves which is quite useful but then because they're quite popular because it's quite a good way to

461

engage people these the quite- they're already taken over as people can be noticed my bit ly on do i do i wait for that do I not? And I kind of research all that beforehand to kind of see what I'm going to expect before I go so I'm not kind of going in and all that know where do I go and what to do. I'm going to have an enjoyable time here.

Ashley Fisher
Have you done any research into treasurer's house?

Jessica
Yes, I do some research this morning.

Ashley Fisher
Excellent.

Jessica
And I saw that in some of the room Did you have the headsets and stuff like that? And I found Treasurer's House website quiet hard to to navigate. There wasn't much information on the They're about what there's there's quite a lot of the ghost tours, yes. What kind of I didn't believe through that website, it's kind of find out about treasurer's house because it wasn't about like, there wasn't like a about us page or anything like that it was only like a little snippet about the actual house itself. It was kind of funded by, and the Roman road nearby and stuff. But, yes, I kind of mainly use different websites and stuff to kind of find out a little bit more about the history and stuff like that. And I didn't see that they had an audio guide. But yeah, as I said, like in the pictures and stuff, I saw that it did have the headsets and stuff and some of the rooms and which is something that I would naturally kind of go towards to when I'm visiting the museum.

Ashley Fisher
Excellent. Now, were there any particular websites that you found useful outside of the

Jessica
So mainly, and I know we've always been to told  to stay away but I do enjoy using Wikipediajust because and it does just have like simple facts. And obviously I'm always very cautious when I'm you know, information is very accurate but just for the purpose of just kind of finding the base understanding of the concept, you know, when it was builtor you know what it's good to see there and stuff like that just living on the history. I do like using Wikipedia, YouTube as well. And for any kind of videos I haven't done on it. I didn't find any treasurer's house in my search. And then I also I do like to use the website and using my read aloud kind of software and stuff just to kind of find out more information about the website and the opening times and stuff like that. And so TripAdvisor as well. I used to have a quick look on that to see what people have said, but the actual place itself and there's usually quite a lot of people talking about kind of wheelchair access and kind of how they found it and that the accommodation, how the staff was and stuff like that. So that's quite useful to know, as a, as someone who has a disability to kind of see the kind of atmosphere that's kind of at the other place, because I visited some museums in you know, Eastern Europe, but that is not the same as here in the UK

Ashley Fisher
a little bit different. All right. So you said that you used a read aloud program? Yeah. Anything else that you use?

Jessica

Um, so yeah, mainly use reading read aloud and my color overlay. And mainly when I'm just doing just kind of research about museums and stuff like that. I don't really use any extra software like that. Yeah.

Ashley Fisher

Excellent. And that's all on your laptop. Do you have any on your phone or anything like that?

Jessica

Yeah. Okay.

Ashley Fisher

Excellent. When we're done, I'm going to show you a really cool app that might change the world really exciting. So when you're physically preparing Is there any specialist equipment or aids or things like that, that you need or that you plan to bring or anything like that. So

Jessica

sometimes, I'm going to a museum that I know that I do really want to engage and I'm really excited to go about and I do have a little color overlay that I can it's just kind of like pocket size, I can just take that with me. And I find that quite useful. But again, if there's people around, I won't usually use it because I'm quite embarrassed. So I only do that if I get a quiet moment alone. Or if I'm going during like a really quiet period of time, and there's not really many people around like okay, I can probably get my overlay out and maybe because sometimes what I've noticed and some of the museum's when they kind of like to have like lighting behind the panel and stuff like that is the I can't see anything at all. Yeah, there's just the the light is just kind of too. Yeah, it just kind of messes with my eyes too much and I just can't even read it a

Ashley Fisher

kind of like a backlit thing.

Jessica

Yeah.

Ashley Fisher

Okay.

Jessica

So in that case, if there's no one around kind of sometimes using my, my overlay can help a little bit but again, I'm sometimes a bit too embarrassed to get it.

Ashley Fisher

All right, are there other eventualities that you plan for.

Jessica

not really I mean, I kind of plan for if, if the museum is going to be busy, and if it's not going to be very accommodating to my disability, then I'll just know that I'll just do a quick walk around the museum. Maybe if there's any videos, I might watch them and then I usually just leave Yeah. It's sometimes that that just just happens. I'm just not engaging with it. And there's no point of kind of giving myself a headache Yeah, it's just not gonna be good for me in the end.

Ashley Fisher
So do you do get actual physical side effects?

Jessica
Sometimes Yeah, if if you know I'm quite tired anyways. And you know, there's quite kind of glare-ish lights and stuff like in Primark a few times when I was younger, I did pass out and stuff and obviously I just didn't realize what it was when I did my mom just thought it was part of my heart condition. But when I had my tests when my Erlen's in July did mention about the lights in Primark sometimes she did I did pass out she was like, Yeah, I've had lots of people had that before. Because they're so bright and so like, yeah, it's just really weird. And so sometimes Yeah, if I'm a bit light or not, I can't handle these lights. Yeah.

Ashley Fisher
Okay. Okay. And how much time does it normally take you to get all of this together. Um,

Jessica
if I'm just kind of planning for, you know, one trip to a museum, it might only really take me maybe about 20 minutes of research, maybe a little bit longer. I'm really interested in the place that I'm going to or if I'm planning like a long trip somewhere like a weekend in Edinburgh, then I might kind of maybe take some notes on my phone. And then when I'm kind of there, I kind of remember which museums about which and stuff and I can kind of just kind of quickly refresh my mind and stuff. So if it's like a longer trip, when I'm visiting a few places, it might take me maybe an hour or something like that.

Ashley Fisher
Excellent. So let me give you a couple of details about our trip today. So we're doing what we've dubbed a semi structured visit. Okay, basically, by and large, I'm going to follow your lead. Yeah, we'll go where you want the museum spend as much time as you like in it, whatever you like. I want this to be as normal a visit for you as possible. That being said, there are a few basic points I want to make sure we hit hence the semi structured so we will visit a particular exhibition room for the trash. House, we're going to spend some time in the sitting room. Yeah. Which you probably will anyway, you're going to ask a member of staff for help. Yeah. And we're going to purchase a small item from the shop, I have five pound note that you can use, don't worry. And then we're going to visit the toilets. Okay. Pretty basic ones that almost everyone does on a regular trip. So it just helps me to compare visits amongst my participants. Yeah. So that we all have certain points that Yeah, I can actually directly compare them. Like I said, after museum will go to nearby pub, have a drink or lunch or whatever, and do a bit of a debrief. You've got the questions for those as well. And I want to do a visit audit with you. Okay. Basically, we'll go through a checklist, see how the museum did in certain areas, like levels is actually one of the things I was very interested in. So this is great. How easy to read signs worth things like that. Yeah, that makes sense. Yeah. Excellent. All right.

## 7.2. Site Visit.

Our visit to Treasurer's House took place on the same day. A technical error meant that the audio recording did not work.

## 7.3. Post-Visit Interview.

After our site visit, we walked to a nearby café to conduct this interview, still on the same day.

Ashley Fisher
Alright, so we just came back from the abbey house there we go. All right. So how did you find walking there?

Jessica
Um, yeah, it was it was fine. I'm using Google Maps and it took  straight to the to the actual place itself obviously wasn't really sign posted I didn't realize I was there until I saw the sign that says treasures house and the actual work itself was was fine to me. Okay. Well,

Ashley Fisher
Okay well, I have a Treasurer's House pen now so it's fine wasn't really signposted Google Maps.

Jessica
Yes. Okay. Yeah.

Ashley Fisher
Do you think the museum could have provided any more information about how to get there, or

Jessica
I mean, I think it is kind of in the center of York and they did kind of say that it was by the Minster on the website, if I remember correctly and obviously, the Minster is quite easy to find. Once you kind of situated yourself from the Minster then I guess, you know, you probably would be able to kind of see, okay, that's where Treasurer's House is but obviously from the way that we came from it yeah you know, there was no kind of sign post and just kind of what it was handy to have the sign outside that said, Yeah, Treasurer's House otherwise I would have walked straight past it. Yeah. And to that, for the fact that he had a sign outside was quite handy.

Ashley Fisher
Excellent. So let's go through our museum audit. Was it easy to find the entrance to the museum from the street

Jessica
yes I was going to go into the of entrance and then it says this is the delivers entrance into the main entrance

Ashley Fisher

465

was the layout of the museum easy to understand

Jessica
I mean it wasn't really clear on where to go as search and but I think that with the there was kind of once you kind of – when you went upstairs and you went down you came back down he went up the stairs he went round and then he went down. Yeah, that that that kind of makes sense. But at first I was a bit unsure of where kind of the actual thing that all all the rooms where it might have been handy to to have a map of kind of where they suggest you to kind of go so obviously people like to take their their own routes and stuff, but there are some times where I wasn't sure whether you could go up the stairs or stuff like that.

Ashley Fisher
was the signage is in the shop? Was the signage easy to understand?

Jessica
Yeah, there was there was a sign that said to the toilets and to the Tea house and then you went straight through the, through the shop, which was obviously their their shop. Yeah.

Ashley Fisher
Was there enough space to move around?

Jessica
It was quite a small shop. Quite No, but I think we were quite quite lucky that it wasn't too busy in there, actually. Yeah, I can imagine that when you get in on peak times at the weekend. I can imagine that and be quite busy to handle but when we were there it was. I felt I had plenty of space to kind of look around and stuff.

Ashley Fisher
Okay. Was it easy to navigate the shop?

Jessica
Yeah.

Ashley Fisher
All right, the toilets. W the toilets? easy to find?

Jessica
Yeah. Yeah, there's a sign that says it was clearly marked which one male and female the toilets were nice themselves. They were clean.

Ashley Fisher
Was a floor clean. Yeah. So Staff. Did the staff members treat you any differently than any other visitors?

Jessica
no, but the members of staff are really nice and were very knowledgeable loves talking about the ghosts They must have like a quota each day of how many times they can mention the

ghosts. You must mention the ghosts at least six times on your shift today. Otherwise you're fired. Yes.

Ashley Fisher
They do mention the ghosts a lot. Was the team member able to offer appropriate help when asked? Yeah,

Jessica
yeah, the first guy when I asked why it was so dark, he explained why and stuff and the lady when I asked her what the toilets was she, you know, kind of gave more of a direction. She kind of went downstairs and then kind of met next to the Tea Room rather than just saying, oh, they're just downstairs. Yeah, she kind of explained there and directions and that, which was good.

Ashley Fisher
Okay, did you feel welcomed at the museum?

Jessica
I did. It was Yeah, it was really nice.

Ashley Fisher
A great strength the treasure is houses all of their stuff are really really really nice yes which is not the case at all my sites the exhibits in general where the displays clear

Jessica
yeah I mean it was... There wasn't so much information you know you don't have you know wall to wall full of information compared to some of the museum's have been in so obviously you did have the the panels, which were kind of broken up into themes which was quite nice and then you can kind of you knew kind of which theme you wanted to look at it and in each room then so that was quite nice. And obviously there's some of the way that the photos were positioned within the text and was quite difficult to kind of then be able to concentrate and read. And obviously some of some of the panels they hadquite a lot of bold writing on and some Itallics that made it quite difficult to read the actual the in depth one, which had one, it had like a little.. in the corner 123 you know, which generally mean and they were quite nice to read and it wasn't you know, didn't have too much information on it. And the actual panel itself was quite light and quite small to handle. The actual background was went quite like quite went quite nicely with the actual text. So that was quite enjoyable to read in each of the rooms and stuff.

Ashley Fisher
Excellent. Were the fonts easy to read.

Jessica
So yeah, I think in most cases and the fonts was was quite nice. I think there was one case where sometimes on the on the theme, text panels, and sometimes and you know where the the image Was it kind of emphasize that the text that they were using kind of made it quite hard to read in those cases? So overall the fonts that they used was quite nice but kind of was exacerbated with different kind of things like the the image and the lighting and stuff like that.

Ashley Fisher
Okay, so it's more the context of font. Yeah, it was what let it down.

Jessica
Yeah, exactly.

Ashley Fisher
was the color contrast appropriate?

Jessica
Yeah. So what I quite liked about all of the the, the panels that you could handle is that it was an on bright white paper and the the smaller one it was kind of creamy and then the themes ones It was kind of like a like a Bluey kind of tint or a Greenie kind of tint or, or a purple kind of tint which is kind of what a color overlay is anyway, so that that made it quite nice and actually read against the text itself. I think that if it was kind of bright white, it would have made it a lot harder. And so the actual with the contrast between the actual background and the the text itself is quite nice and also when we went up to the the top room and that was quite nice as you said, Actually with the brown writing and especially compared to the black one that was on the wall even though it was the same color background it was I see a lot easier with brown because the the kind of the contrast was a lot lot smoother, but the black and white kind of thing.

Ashley Fisher
Okay, how's the volume of the videos cuz you watch one with the headphones?

Jessica
Yeah, so yeah, that that was fine actually, I think obviously with having the headphones on is naturally a noise cancelling and kind of tool anyways and I thought You have the volume was perfectly fine. And which was which is quite handy because I know I have been in the Yorkshire museum and they have videos on and you can't hear a thing and then didn't even have subtitles and you're like what's the point of this?

Ashley Fisher
Yeah, exactly. where the stories and Tales of the experience easy to read and understand

Jessica
yeah that I'm the guy what was it called

Ashley Fisher
Frank green

Jessica
He didn't seem like a nice person! have it was quite interesting to kind of his personality was very much reflective said in the materials that I was reading and it was it was quite amusing. And so I think the aspects of it was it was quite nice and then in kind of each of the rooms and stuff we tried to make like a person of interest in it so you had princess Victoria and and I was like the King's room and stuff like that. So that made it quite nice instead of just being

468

like here's here's another room isn't it's pretty kind of thing. Yeah, it's quite nice actually tried to make it a person of interest and how how the actual room would have been used when the house was in function. So I thought that was that was quite a nice thing and you can easily will relate to it because you're kind of putting it to kind of persons and stories and stuff. Yeah.


Ashley Fisher
So it's much more of a narrative stories rather than just


Jessica
Yeah, yes, actually. Yeah.


Ashley Fisher
Right was the overall noise level appropriate?


Jessica
Yeah, I think in those kind of places anyway. Everyone's always speaking in in hushed tones. And so so that was quite enjoyable because what I found in different places and stuff when it when it is quite loud when you're trying to concentrate on being and stuff and you are finding it quite difficult so then have another kind of like annoyance in the background coming quite difficult so the fact that it was quite quiet when when we were there anyway but people you know do real always can speak in hushed tones that was that was quite all right yeah


Ashley Fisher
yeah okay with any places that you thought it was too loud or echo-y or anything like that


Jessica
I guess like down in the basement area because obviously it is quite echo-y anyway and obviously it was like you had the tea room there as well and the shop and stuff so there is not actually going to be a lot more chapters there anywhere and obviously when you when you come in at the reception area that was obviously quite loud as well, but that's just because they're just their general areas. Yeah.


Ashley Fisher
Were there any places you thought were too quiet?


Jessica
No, not really, I don't think anywhere could really be too quiet in these types of places. So no I don't think that was anywhere that was too quiet.


Ashley Fisher
Okay. Now lighting levels Okay, the fun one was the lighting level appropriate


Jessica
for me No. I mean it is tough for me because you obviously know why they don't have a lot of the natural light coming in because of conservation reasons and stuff. And but I you know there was I think that the type of lamps that they were using didn't help either so obviously

like It Wasn't that type of like bold It was quite like an orange one which doesn't give a lot of light anyway if you had like a like a light like that, that that does get quite a lot of light. But the other one the user could read both Yeah. Which was which made it look even dimmer to be honest. Yeah, and there was it couldn't imagine being in there in like peak winter. Yeah, like The guy who was speaking he was like us come three o'clock is just pitch black in here you can't see anything nevermind me what about for other people like that must be a quite a hard experience. But some rooms were better than other but that was just precisely because of the natural lighting that was available so if there was a bigger window, but generally I found it quite a dark place. Yeah

Ashley Fisher
Right. I finished the audit and then yet because we got two more questions. So do you think any of the places were too bright? Um,

Jessica
I didn't think that they were Thank you Thank you so much. I think there were there were too light as such I think that when we went up into the top program and that was that was quite a light space but it was quite nice because the walls were quite liight and so with the text panels and actually kind of blended the room quite nicely together. And I think that if perhaps you had like a video in there for example because it's quite, quite bright it would be would have been struggling to see it. And I think that the fact that the left it just as text is quite nice actually. Okay. But there was like some cases because obviously in the in the dark rooms It was really dark in the middle and then it was really bright by the by the windows and then with the with the the text booklet that was in the shiny material because then that light was in kind of shining on it, it made it really well impossible to read it really bother with any of them.

Ashley Fisher
Yeah. Okay. So we're some places to dark. think I know the answer to that question, but go ahead.

Jessica
I think the worst room was in the king's room when it was all the whole room was red. And because obviously you've got a very dark kind of colors in the room. It just makes it completely dark. And they also the room when they had the ship in the middle of the ship that was really really dark. I just didn't really bother reading anything in there because it was just given me too much of a headache.

Ashley Fisher
Were there enough places to sit and or rest?

Jessica
I think there was Yeah, it's in the I mean, not in obviously the actual house itself. There was a lot of chairs, obviously, you weren't allowed to sit on them. But when you went and the upstairs pause in the locker rooms, there was quite a lot of places to sit there.

Ashley Fisher
Okay. I did notice you sat down, not immediately in the one big bright room but I did notice that you sat down. Yeah.

Jessica

Very interesting,

Ashley Fisher
because there's actually a chair in each room But I don't think they signpost them very clearly. At all. Yeah. So. All right. we've already gone over the fonts and the color contrast they're pretty much the same around the around the museum. And you think the stories and the tales in the sitting room were easy to read and understand.

Jessica
I really enjoyed the in depth panel once it's about the vases and stuff that was quite nice to to read. And then the theme panels there was a lot of mentioned about the the little like niches that was on the floor. That guy put down a little press and yeah, so then he knew that none of the furniture would be moved as yeah

Ashley Fisher
But that was honestly one of my favorite things about treasurer's house

Jessica
and that's when will I I remember kind of be in on the panel and I think there was some like other stuff about the actual room itself natural desperation and I don't think it was that engaging in that particular room but as I said the in depth panel was quite interesting and and they're not just on the floor was quite fun to look at.

Ashley Fisher
Okay. noise level, how was it?

Jessica
Yeah, it was. It was fine. I didn't particularly notice anything that was too loud or anything like that. Okay.

Ashley Fisher
And lighting is that Yeah,

Jessica
so it was quite dark in that room because it was quite a big room. It has some windows but because it was quite big. It was quite hard to light up that room. Because the was a lot of windows, there was the ability to kind of go over to the windows to be able to kind of be able to read the panels and the text a bit clearer. But if it was like a busy day, for example, and it was quite busy, I probably would feel a bit too self conscious to do that. So I probably would have just skipped past that room if it was quite busy. Okay.

Ashley Fisher
And he said something about how there they were trying to recreate how it would have looked like when Frank green was there, right.

Jessica
Yeah. So he mentioned about like, and what they what they would have done when the house was an operation is that they would have put like the candles and stuff by the mirrors

471

so he kind of made the room a bit lighter. And that's it. He said that's why they kind of had some of the the lamps and stuff in front of the in front of the mirror just to kind of mimic and what would have been done He said, That's why they don't have like overhead lights and stuff in there because we try to make it as authentic as possible.

Ashley Fisher
Do you agree with it?

Jessica
Um, I mean, kind of Yes, in the sense that, you know, people do go to these kind of places because they want to kind of  step through history and stuff like that. And obviously, if you start putting a lot of modern additions in there, then it is obviously going to, to spoil the authentic feel of it. But I think that in that house in particular, it's just very, very dark. And I imagine that people would rather be able to see that not see at all so even the addition of just you know, some lighting I think not would wouldn't ought to be beneficial for me, but for you know, like, a lot of people because there's quite a lot of people You know, older people in there, the elderly, and I can't imagine that they have, you know, perfect 2020 is

Ashley Fisher
that is the National Trust main demographic? Yes, we're honest. Yeah.

Jessica
And so like if I went in there with my grandma, for example, I mean, I think that she would have definitely struggled to see because of the lighting itself. Okay.

Ashley Fisher
Were there enough places to sit and or rest and sitting room? I don't.

Jessica
I don't recall seeing any seating in there to be honest. I mean, I think you could have sat on the windowsill, but I'm not sure if that was neat to see. Yeah, there were there were people sitting in one of the windowsills at one point, and they didn't get told off. So I guess it's okay. But yeah, it didn't really make it obvious. Yeah.

Ashley Fisher
Alright, so one good thing and one bad thing about the museum in general.

Jessica
Okay. One good thing. I'm I really enjoyed the top room. And the exhibition, we had a fair talking about the kind of the loss of the many houses around Yorkshire and stuff. But that was quite interesting actually, I think that a lot of people would have kind of read that and kind of be like, okay, like, this is why these kind of places are important. And I thought that it was quite nice actually, to kind of round it all together. And kind of not as you think about the history itself, but the actual, you know, kind of overall theme of it and stuff and it was quite nice because it was quite light in that I quite enjoyed being in that room and also quite liked how on the wall they had kind of like all the list of all the houses and stuff like that, but that was a quite a nice way to do it. And I also quite enjoyed interacting with that wall in particular as well.

Ashley Fisher
Okay, one bad thing. About the museum in general. So

Jessica
I was said the lighting, definitely.

Ashley Fisher
One good thing related to accessibility about the museum

Jessica
is that it you did have the individual panels that you could pick up, you can kind of pick way which is quite nice for me because then I could put my overlay on it and not be embarrassed that people are trying to read it with me or anything like that. It was like my own little kind of panel for five minutes. I was having it. So that was quite nice actually. And it means that not everyone is kind of standing around one panel, people like to pick it up and then take it around the room with them. So that was quite nice, actually.

Ashley Fisher
Okay, one bad thing related to accessibility.

Jessica
And probably the lighting thing

Ashley Fisher
Okay, did anybody jumped out at to jump out at

Jessica
you. Probably the lighting lighting again. Yeah. Probably the main thing Yeah. Because while the the panels you know that they were great and obviously sometimes were that they were laid out and made it quite hard to read and stuff like that book if the whole place was a little bit lighter, I think I would have enjoyed it a lot more. Because even though you know the actual text itself might have been hard to read at times, but that the aid of being able to see and stuff like that would have just made it a lot more easier and a lot more enjoyable and easier to engage. Yeah, I think the lighting was it was a huge kind of barrier in the place itself.

Ashley Fisher
Okay, were there any access tools that they provided that were helpful?

Jessica
I mean, I think the fact that the the panels were individual was was quite a helpful Access Tool. And I think that the, the video that we watched in the kitchen and that was quite nice to have been the fact that you had subtitles on it as well. Text to read and stuff was was quite nice and stuff like that, that helps me quite a lot engage. And also saying that the video downstairs as well in the basement and had headphones, and it had subtitles as well. That was quite nice.

Ashley Fisher

Excellent. Do you think the museum could provide anything else to help?

Jessica
I think you kind of what you said and I'm thinking about it is the fact that if they had and kind of the panels on the website, you can perhaps download so obviously the perspective it needs to be dark in there of see if you have even phone and stuff like that and you can adjust the brightness to how you would like it you know if they had a downloadable guide and they kind of mentioned when you're in this room you read like this titles of someone that doesn't have to be in depth as the theme panels for example but the the other like in depth one and which was quite nice having the room that might be good to have as a as a website version.

Ashley Fisher
What should the museum design into the exhibitions from the beginning to be more accessible?

Jessica
And I think that perhaps I'm kind of like two panels, okay, especially for me, for example, it was quite hard to kind of navigate my overlay and the heavy panels at the same time and stuff and I think that the doing quite good job ensuring that the panels aren't on pure white background, but I think that perhaps not having as much bold on the panels and maybe not italics, there is another, you know, there are other ways that you can emphasize quotations about being in italics and stuff like that. Yeah, definitely. And kind of the fact that I'm quite a bold writing on the other panels. Okay,

Ashley Fisher
so more around the design of the font suits and things like that. Okay. And obviously, you brought your overlay.

Jessica
Yeah.

Ashley Fisher
And used that. Now, it's okay to say one way or another, were you using it more often because I was there watching you, or is that about how often you use it?

Jessica
I think that's about how often I would use it. I think that in it. I was able to use a lot more because of the individual panels themselves. I've been in museums where it's obviously just on The wall and I don't really have the chance to use it. And I sometimes use it when I get getting guidebooks and stuff like that in museums. And I felt like I had to use a little bit more because of the lighting. And if it was a lot lighter in there, then I may have not used it at all.

Ashley Fisher
How did staff make you feel?

Jessica
That's what they were. They were nice. And they were very friendly. Yeah, I don't really have any complaints about any of the stuff. They're good.

**Ashley Fisher**
Good. do you think you would have been treated differently if your disability was physical?

**Jessica**
Yes, I can. Maybe not in a negative way. But I do feel for example, that they might have tried to help about being about asking about asking for help and things like that. I think that People are more prompt to say what is help here. You have a disability that you can see. Sure.

**Ashley Fisher**
Interestingly, when we were in there one of the upper rooms, there's a gentleman that I think had Down syndrome. Coming consistently a room behind him. Yeah, yeah. And the person in that room was very good with Yeah, very patient. Very helpful. Yeah.

**Jessica**
Yeah. really engaged with him. Yeah.

**Ashley Fisher**
If you could tell the museum one thing regarding the accessibility of their site, what would it be

**Jessica**
and to make it more accessible into the lighting? Okay, I understand the reasons that they have done it but perhaps, I don't know. They would maybe want to make a make it known on the website or something that it is quite a dark place. And and kinda of, you know, provide kind of online resources that people can bring on their own devices. And I think get kind of maybe making people aware that it is quite a dark place. Sure.

**Ashley Fisher**
Right, that's all of my question. Yeah. So do you have anything else that you want to say about the museum?

**Jessica**
No, not really?

**Ashley Fisher**
All right.

## 7.4. Follow-up Interview.

We met at a café in York on 25 October, 2019 to conduct this interview.

**Ashley Fisher**
So I'm just going to go back over some of the things we talked about last time. Yeah. You came down quite hard on the lighting in, in treasurer's house. You still feel that way?

**Jessica**

I do, okay. I mean, it's quite coincidental that we're also in a place that doesn't have brilliant, but um, yeah, I was kind of thinking back on it today when I was driving home from work. And, you know, it definitely was a huge issue, I think, for me, and I think we were quite lucky that we were there to on quite a bright day as it was. Yeah. So I think that if we did go, you know, kind of more in the wintertime when there was kind of less light available anyway, I think that it would have been a lot more difficult to kind of engage with the material in the actual and the museum itself. All right.

Ashley Fisher
You said that the staff was amazing.

Jessica
Yeah, yeah. Yeah. Well, this staff were really really nice. You know, when I asked where the toilet was, for example, because they kind of just say, Oh, it's just downstairs, it kind of went kind of above and beyond them and like, give like, the more detailed instructions and, and kind of the stuff that I saw interacting with the other visitors. They were really great, really knowledgeable the mentioning thing about the famous ghosts. And in the basement, and yeah, I thought yeah, the stuff were really nice.

Ashley Fisher
would you do you think they were a highlight of visiting there?

Jessica
I think yeah, I think because, in particular, you know, I wasn't really able to engage that well with the material. So it's great to know that you do have staff that you always want to kind of interact with, and still have a meaningful experience coming up to ask questions and get quite a lot of information from still Yeah.

Ashley Fisher
Yeah. And you like the handheld panels?

Jessica
Yes. So I think positive of them was the fact that they were kind of my own personal panel I could use my an overlay on like, for example, if I'm in certain museums and heritage sites where it's just big panels, yeah, obviously everybody else is kind of around, you're looking at them, I don't really want to be kind of sticking my overlay on a on a panel that everybody else is looking at. So that was a definite big advantage. Yeah. Of kind of a not horrible situation. But it was kind of like the silver lining for most of that.

Ashley Fisher
Right. And you said you probably wouldn't visit the museum again. Is that?

Jessica
Yeah, I think because it was quite a typical experience for me. And I felt that if I went again, I probably wouldn't be able to have a meaningful experience. So I wouldn't I probably wouldn't visit there. Again, if I was interested in kind of finding out the information or probably do my own research, kind of maybe watch some videos and listen to some podcasts or something like that, rather than actually visiting the museum itself. Okay.

Ashley Fisher
Did this museum remind you of any other museums that you visited?

Jessica
Um, it kind of it was very similar to Gawthorpe Hall in Burnely. And which is near from where I'm from. It's a very similar in terms of the lighting because the opposite was house that was actually lifted to the lighting is very much restricted, and it's kind of preserved, how it was lived in. Yeah, so basically. And so it was very, very similar to kind of that kind of visit that I've done.

Jessica
Previously in Burnley.

Ashley Fisher
Do you think that's a general issue with like, Manor homes and heritage sites like that? Yeah,

Jessica
I think, you know, they're all quite similar and you know, kind of like, Castle Howard is another kind of one, that does come to mind is that you're trying to protect It is found and so there's not really much way for kind of, you know, adding you know, modern features like lighting or perhaps panels that you know, kind of do have a fly or, or video stuff like that because we're not really able to kind of put that in. So in a so much lack in kind of the modern technology and additions that you might find in a museum, for example, that's been built to be a museum.

Ashley Fisher
Are there any stellar museum experiences that stand out in your mind from places you've been in the past? So

Jessica
my favorite places in York is the Minster undercroft. Yes, okay. I do really enjoy that. Even though obviously, there's no natural light, there is quite a lot of artificial light, which I find to work quite well with my disability. And there's quite a lot of kind of different interactions there's videos there's kind of like build your own arch which I'm useless – I guess I'm and you're actually able to kind of engage and see the actual kind of like Roman road and the walls and stuff like that. And for me like that is kind of like what I compare everything to and it's probably one of the my favorite places to go. And another very good place that I've recently been to was in North Macedonia of all places, really, I went to the Holocaust Museum there. And it was spectacular. It was really really modern. A lot of money had been put into it. And, and the, you know, it just had a great array of different kinds of interactive panels, video, and headphones. had kind of you know, That you could interact there. And it was quite emotional. You kind of went into like carriages and stuff like that. And you were really it was very immersive. And I feel that for me, it wasn't it wasn't just kind of standing around reading, it was a lot of interaction, which is something I really enjoy things. I'm just going around reading, because I find it difficult to kind of read interactive panels as it is kind of being able to kind of do it in a different way. Sure, quite nice. So I another example that srings to mind is the Liverpool Maritime Museum. And they had a slavery exhibition. And that was exactly the same. It was very immersive, very interactive, you weren't just kind of stood around reading panels. You have been very much engaged and there was lots of videos and audio files and stuff like that.

Ashley Fisher
One of the things that I'm seeing sort of common throughout this is that there's lots of different ways that they're presenting information. Yeah,

Jessica
exactly. So it's not just one standardized way of it just being kind of interactive panels and the objects that see it kind of, you know, a very immersive you know, I find that I do kind of learn by kind of listening and kind of seeing and kind of like interacting and stuff like that, rather than just reading it. I'd rather listen to things and learn that way, rather than just reading a piece of paper.

Ashley Fisher
Yeah. Do you think there are different expectations put on paying versus non paying museums?

Jessica
Oh, that's interesting. I guess, in terms of, you know, on the funding side, yeah. If you're paying something You expect it to be good almost Yeah. You know, you're you're paying for a service. Well. If it is free kind of museum you know you do have your expectations are a lot lower because you're not paying for that service. So you're almost your you don't mind this is not as much of a engaging experience. Sure. Then if you're paying for it, because if I'm going to a museum and I'm paying 10 pounds to get in, and then I realized that I'm I am unable to engage with anything because they haven't you know, it's not really catered to my disability, yes, that I'm going to be but like, well, it's just pay 10 pounds to kind of come here and I'm not really having, you know a meaningful experience. You know, and if I'm paying then at least they should be able to have maybe an audio guide for me to use if I if I am paying like, if I go somewhere that's free. And I'm not that bothered if I am not been able to have meaningful experience and I have to kind of leave after a short amount of time because I haven't paid kind of thing, right?

Ashley Fisher
Do you think that the treasures house would have been value for money basically.

Jessica
Um I think that if I paid, I'm probably not know. Because, you know, I didn't mean to have a meaningful experience and  If I am kind of paying for service, I might expect perhaps that be an audio guide or online resources that I can use around the museum itself be able to have a meaningful experience rather than just kind of reading off an interactive panels. Yeah. And I think on that side of things, I probably wouldn't be inclined to go Again, if I definitely knew that I had to pay, yeah, because I knew that I would have a meaningful experience.

Ashley Fisher
Yeah, sure If we had taken this trip on a bad day, would it have changed anything? And what would that bad day be? Like?

Jessica
What you mean, my bad day?

Ashley Fisher
 Um, well, for some people like arthritis flare ups, but I think it would be more of a very dark day.

Jessica
Yeah. So like a dark day, or perhaps I had a bit of a headache that day, for example. So I think, could you repeat the question? Sorry, yes.

Ashley Fisher
If we are taking this trip on a bad day, would it have changed anything? And

Jessica
I think probably not, no, because I think the experience on the outcome would still have been the same because I didn't have a meaningful experience. And I think that nothing could really affect that. I think even if it was, you know, a bright summer day and there was kind of, you know, a bit more life and I think that the light still would have not been enough. Yeah. And maybe for example, if I did have a headache, and I was finding it difficult to read more than I normally would, I might be inclined just to not bother reading anything at all. Yeah. But overall I say, on the whole, it doesn't really make much of a difference in general. I didn't really have a meaningful experience here.

Ashley Fisher
So it's, in general, a disappointing experience.

Jessica
Yes.

Ashley Fisher
Okay. Fair enough. Now, this is probably my most invasive question, but do you consider yourself disabled?

Jessica
Um,

Ashley Fisher
there's no right or wrong way. What I'm very genuinely curious about

Jessica
I think that when I sit, I'm kind of look at that I say that because you know, on the disability spectrum, you know, I'm very, very, you know, mild. I know that a lot people who have you know, worse Irlen Syndrome a people have worse dyslexia than  I do, I feel like on the spectrum I kind of I feel like I don't have the right to say that I have a disability for definitely when you know for example when I was writing my my essays for my msterss you know I needed the disability help like I needed that so often in that case I did class myself as having a disability because kind of compare myself against my peers in my class. I very much could see that I had a disability. Yeah, but in kind of the the wider world. I mean, on job applications I don't put down that I have a disability because I didn't feel like it would affect my job that much and I feel like it is relevant for the job I do now is definitely not relevant at all. Like in my on my Word document I have my like, background- I do have my overlay

colour and I did I've had to tell my team leader, but when originally I was hired. I didn't feel like it was relevant.

Ashley Fisher
Yeah. Fair enough. Would you then say that you are a person with a disability or a disabled person?

Jessica
A person with a disability, I think.

Ashley Fisher
interesting to me, there's a lot of debate as to whether we should be saying disabled person or person with a disability. But it mostly affects people with visible disability. Yeah. And as I'm doing more of this research, it's becoming very clear to me that people with hidden disabilities don't identify as

Jessica
If I told somebody I have Irlen syndrome, I don't expect them to say you're disabled, I would expect them to say, Oh, so you have that disability. Yeah, I yeah, I would never kind of make that. Yeah, I would never say that I'm disabled. I said that I just have a disability.

Ashley Fisher
Obviously, there's no research on this whatsoever,  so I'm finding it very, very interesting. Yeah.

Jessica
Because disabled is such like a like an overt term it's like characterizating That's who you all you would play with as you are a person with a disability kind of insinuating that you have a lot more layers to you, you are a person that does have a disability. But there's more to you than Yeah,

Ashley Fisher
yeah. It's very, very interesting because, for example, people who use wheelchairs, they very much identify as a disabled person because, yes, there's other layers to them, but everything is touched by the fact that he is a wheelchair. Yeah. But, you know, with dyslexia, that doesn't necessarily mean everything about you is touched by it. Yeah. You know, exactly. Yeah. Very interesting.

# 8. Kasi & Teagan.

Kasi and Teagan are women and sisters. Teagan has dyslexia and EDS. Kasi has ADHD, dyslexia, dyspraxia, and EDS.

## 8.1. Pre-visit Interview.

I met Kasi and Teagan at Teagan's home to conduct this interview on 31 May, 2019.

Ashley Fisher
So you guys know what my research is?

Teagan
Correct.

Ashley Fisher
Have I explained to you what it is? So I'm looking at people with hidden disabilities, and how museums can better make their museums accessible for them. So First things first is the consent forms. I have copies. I know you sent them to me, but here's a paper copy, go ahead. Fill those out, here you go. Three different meetings that we'll be doing in regards to this. This is the first one, and on Sunday, we're going to have our actual trip to Abbey House Museum in Leeds, and then there'll be one sometime next week, thinking about Monday. Very flexible when it happens. Just as a sort of follow up session.

Teagan
(sounds of agreement as they fill out the forms)

Ashley Fisher
Alright, Can I get your signature there? That's fine. (giving the date) 31st. Do guys have any questions? Before we get started? Okay, that's fine.  So today, we're going to go through a couple different things. One is, you know, your pre visit research, and what do you guys look at and things like that? And then I'm going to have you walk me through how you get ready on the day to go somewhere, just to see what it is. I have a couple questions for you Before we get started. So we have gotten started. But still. These questions are in regards to your disability, so you are absolutely free to tell me no, I don't want to answer that.  All right. So you guys have something called Ehlers-Danlos Syndrome, is that correct? Yes, I've done some research on that. But can you guys tell me in your own words, how those, what they are and how they affect your everyday life.

Teagan
So Ehlers-Danlos Syndrome is a connectivity problem, specifically it means that my body does not correctly create collagen, so it can affect every connectivity tissue – connection in your body, from eyes, joints, digestion issues, hearts and everything like that. The specific type that we have is the hypermobility type. Of the different types, it tends to be the most benign, but it can also cause a lot of issues. One of the problems with it is that just because you're feeling good one day doesn't mean that you will continue to feel good the entire day or tomorrow, regardless of what you're doing. You can do something as simple as taking a step like I did today, and I sublaxed my knee. And my kneecaps are currently in the incorrect place, and there's something underneath, which makes it feel very strange. Okay, So in addition to that, with me, it means it also affects my digestion, so I cannot eat red meat. This is not typically come up as an issue Very often. But it does mean that every once in a while, we'll probably need to sit as we're going around the museum. In addition Ehlers-Danlos syndrome, a common problem that is associated with this is a thing that's called POTS. Which the long name for it is like, Let me look it up real quick. (muttering as she uses her phone to look up the full name) It's postural orthostatic tachycardia syndrome.

Ashley Fisher
Okay. Basically, your heart changes your heart rate changes based on how you're sitting, or what position you're in.

Teagan

What position you're in. Yeah, it's the strange thing about it is... an easy way to say it is if you stand up too quickly, you pass out. Because your blood flow doesn't go very well. But what it primarily affects us is we can't stand in one place for too long. Because by not standing, it actually causes our heart rate to decrease, which then increases the blood flow rate, which causes us to get lightheaded and that kind of stuff. Yeah. Yeah. Do you have anything else to add on that Kasi?

Kasi
On the EDS thing? I walked a bit too fast yesterday, and I pulled the back of my le.g. Okay. That's fine. Okay.

Teagan
Why don't you talk about more the hidden disabilities parts since yours is more significant?

Ashley Fisher
Yeah and then you also have dyspraxia, is that correct?

Teagan
Where you keep on running into things. Okay.

Kasi
Yeah, I also have ADHD. Okay. But I tend to not act out as much. Sure.

Teagan
It's gotten better. But I think that's because she doses herself caffeine which helps in that regard.

Kasi
It's mostly just a focusing problem, I struggle. Even If I'm really engaged in a conversation, I can get distracted. I can end up spacing off, I have been to a lot. And It's very annoying, especially if it's during class. And I'm like, Hi. We're having a test review. Few minutes later, class is over? Oh okay. Yeah.  When it comes to dyslexia. It's all a processing thing. Whether it comes to writing something down reading something, or just that first like, comprehension of a word can be pretty hard.

Teagan
As you know by my unfortunate handwriting.

Ashley Fisher
I love it. Don't feel that I might laugh, but genuinely, The bright spark my day.

Kasi
And it can be hard for me to understand what it is I'm reading, especially if I don't hear it verbally. Sure. I can read a paragraph and nothing has been retained. Yeah. And it can be hard with understanding how things are pronounced. Yeah. Ups.

Teagan

I think my my best example, was fatigue. So I just assumed most video games there was this magical thing was magical or called "fat-i-gew". So I realised one day was

Kasi
Drawer. I had not realised it was spelled draw-er. Yep.

Ashley Fisher
Excellent.

Kasi
I just lose letters. Okay, And I have to mixed stuff up. I have also mixed up numbers for letters. Fours and Rs, of course, for some reason. Okay. Gs and sixes.

Ashley Fisher
Yeah, I can see that.

Kasi
Spatial processing thing. I get lost very easy.

Teagan
This is how you got lost in Alaska.

Kasi
I did. I am not very good at judging distance. Which is a problem when Driving. Yeah. Especially with stoplights that are further away than the line is that that is it.

Ashley Fisher
Which is horrendous in this country.

Kasi
Rights and lefts. Like, I don't know which one is the right one. What I'm staring at it. They're not there yet. I also can't retain directions ever. Okay. Yeah, Give me one of those like instructions like turn right here. And then left and right and left. It's like I'll remember turn right? Maybe

Teagan
That's why I like when museums use the colour coded maps that corresponds with the area. I just look up and ah, I'm in the red area on the map.

Kasi
But I also have a tendency to, I will look at something. And If I'm walking, I have no awareness of where I'm walking, I got lost in Alaska that way. Also run into things that way. And fall when I trip over, Okay?

Ashley Fisher
Okay, It's gonna be so much fun going to the abbey house museums guy,

Kasi
you're gonna see me grab onto her arm. And I'm looking at something.

Teagan
She grabs onto someone's arm so she can look around.

Ashley Fisher
That's, that's all I had for this section. So we have hang out. So like I said, I'm going to be doing a couple things now. But first, I have little activity. Because during these observation, I can look at you guys all I want, But I want to know what you're thinking. So This is something called the think aloud verticals. And this is just going to help you verbalise your thoughts more easily. You're going to feel really silly doing it the entire time. But That's okay.

(think aloud protocols practice – lots of overlapping voices)

I'm gonna have you guys walk me through your pre trip research. So how you find out what you need to find out for a visit to

Kasi
I trust Teagan to take care of it. We have similar problems. So I assume she thinks about it.

Teagan
[First checks museum's website] first thing I was looking was what time they're open, Okay. I tend to look up and see if I can see an overall map. Not really about access. They're not

Kasi
looking I look at born in America, I went there is how would I feel to get there?  Would I have to walk there? Transportation. Okay.

Ashley Fisher
Sure, yeah. Yeah.

Teagan
Actually, that's true. Stuff like knowing where we were going to, so google that stuff and see where it's located on the map.

Ashley Fisher
Okay, and what websites do you use to figure that out. Google Maps?

Teagan
Google Maps. Okay. I was just wondering where it's physically located.

Ashley Fisher
So first, you would sort of chart out a path to see,

Teagan

484

Yeah, I kind of I would literally go on to Google Maps. typically, if I was to just look in the area, I would pull up and see what's the closest, easiest route to get there. Okay.

Ashley Fisher
makes a lot more sense that you don't do a pre trip research. It takes a lot more sense. In my head. I was like, how can you about plan everything to within an inch of his life? Okay, actually, that makes sense now.

Teagan
I'm gonna pull it up on transport. Yes. And there is a bus that conveniently goes directly to there. If I was feeling particularly good on a day I might consider walk into a location. I've done that with the Rowntree Park,, the National Trust house that was here Afterwards [I felt awful]. But I still did it. I look at accessible area. The access portion of their website is convenient in the sense that it does tell me how close it is to the city centre. It doesn't say the bus route on the first thing I would have thought it would, It just says it's located off the Abbey walk road. from a short but steep hill, and it says for parking. But I would have assumed that anyone needs to take a bus.

Kasi
something I was currently when I get there is an area to rest. it will be hard to... I'll rest against a wall. But yes, yeah, or

Teagan
Or café. This is one of the nice things about us. And the US, whenever you look up these types of things, the maps tend to be quite... quite useful. Because then you then basically all the information like all this information was nice, But but read you can read a map so you can visually way just so you can see like, was just a general.

Ashley Fisher
Okay, so what are you looking for?

Teagan
I'm still looking for a map just to see if they're gonna have one. No. I don't think they're going to be honest. I think they're just gonna want me to read words. The access page? I mean, it basically it does have accessible toilets. But that doesn't really matter to us as much as

Ashley Fisher
well. Yeah. The accessible toilet is, you know at one end of the museum. And you're all the way on the other. That's not super helpful.

Teagan
It's just telling me what facilities are in the toilets, which is really all that important to me. No idea what a changing places facility it.

Ashley Fisher
So changing places facility is for people with more severe mobility needs. Yeah.

Teagan

To be honest, I don't just assume that they had one of those.


Ashley Fisher
Still looking for a map on there?


Teagan
Yeah, now I'm looking in general. So what they're going to be showing, since it doesn't look like there's gonna be a map on here that shows the basic of what it is and what the layout is. They have a physical location, which when I clicked on, Which led to just saying this family friendly and it has wheelchair access, which it already said in other places.


Ashley Fisher
You think it's helpful to have that information in multiple places? Or is it just redundant at that point?


Teagan
I mean, it is useful in a sense, that if you just want to click and see what's on I think this is a different website. Yeah, so I like to see what's on at the abbey museum,  it took me to a different site. It does feel like it's a bit piecemeal in the sense that the information that it has in the access all areas is not as complete as would have been useful. Just, It would have been nice to have the public transportation in addition to walk by car.


Ashley Fisher
Yeah, it'd be nice to have basically all the information on that page.


Teagan
It also doesn't say.. I'm having a hard time finding like what type of things it actually has. So other times by looking at the page, they are showing at the main idea of... like Wow, Look, if they cater towards artists, I Expect the artists to be able to sit, like on a chair you can then take around the museum with you in different rooms, handle different art. They don't always list that they've got chairs, Sometimes you have to kind of read between the lines yet. Actually, I mean, that one picture of the example of the street was the public places you can sit But that doesn't really matter too much. Assuming it's not the size of the British museum. Back to the café. Yeah. Okay. So the things we'll have to find out as soon as we get there, We'll have to get a feel for how large the museum is to get an idea for how long we can go, Just in case they don't have seating. Alright, even if we can't finish the entire museum, we can see a bit just like walking through the end to quickly make our way today. So basically just need to get a feel for how the museum is setup, the location of the toilet and café.


Kasi
bathroom.


Teagan
Yes. That'll probably be one of the first things that you go and use.


Kasi
Probably the last thing I use too. I don't want to go on a public transport [without doing that].

Ashley Fisher
On the subject of public transport, will you do that Right now or on the day?

Teagan
No I plan it now. That's the thing that I tend to always plan out how to get there beforehand. Okay, once because of the lacklustre response to have on websites I tend to... If I can't find what I want, it does have an effect on if I want to go to a place. Because If I can't guarantee that they'll have a toilet or place that we can go and sit than I know what I can't spend a whole day there. Looks like it would take us about an hour and a half to get there. 13 minutes on the bus to get to the station. 30 minutes on the train and 15 minutes on the other bus. I buy bus [tickets] the day of but I almost always buy trains early.

Ashley Fisher
Okay. What website do you use? Or app or whatever.

Teagan
I tend to go with whatever the station is. Yeah, I just tend to go with Because I look it up on Google. First, I see what the main train operator is.

Kasi
Because I rely solely on a car. I always make sure I know where it is and stuff like that. And do I want to park in this area.

Ashley Fisher
Excellent. All right. I notice that you are using your tablet. Are there any specific tools on your tablet that you use? Screen reader kind of thing.

Teagan
I find that if I turn off the blue Light that actually makes it quite a bit easier to just read in general. But I actually don't have the same problem with tablets and stuff as I do with traditional media. White Paper with like black text tends to be much harder to read a white background on tablet which isn't pure white.

Ashley Fisher
Sure.

Kasi
I find that black background, white text is easier.

Ashley Fisher
You, Kasi, come and walk me through how you would get ready On a day. Walk me through everything. This will be very weird. Okay.

Kasi
First I'll Try not to die on the steps. Okay. I fell down on the day I got here.

Ashley Fisher
Excellent.

Kasi
So I Get up. I probably immediately get dressed. Okay, just get a bag, right? I want to make sure I have water. I get dehydrated a lot. Might also have to do with going to the bathroom a lot. I have my phone, maybe headphones. I take a pad of paper with me. If I need to write something for any reason. Sure. I go to the bathroom. Just brush my teeth, brush my hair. But I get the bag. Probably grab breakfast.

Teagan
I tend to like to try and get to museums first thing in the morning because they tend to be less crowded, so it's easier to get to, it's easier to get around, especially with a pushchair. So given that it opens at 10, it's an hour and a half to get there. We would like to grab food that we eat on the way.

Ashley Fisher
Yes.

Kasi
So than I wouldn't eat breakfast here. So then I'd sit here, Maybe have something to drink.  When it's time to go, I'd probably go to the bathroom one more time.

Teagan
Yeah, yeah, man, just depending on how you're feeling that day depends on whether or not Some kind of mobility aid or not.

Ashley Fisher
Okay, What kind of things do you have for that?

Teagan
The primary thing that I keep, that I have on hand tends to be wrist braces or ankle braces. Wrist braces are not likely something that we would need.

Kasi
Unless I thought I would have to be holding something like just anything more, then I'd have [them].

Teagan
Yeah, if I like hurt my ankle or something, I'd take my ankle brace. I used to have knee braces.

Ashley Fisher
I'm going to take a couple pictures of that. Okay.

Teagan
[demonstrating ankle braces] I've got one for each foot.

Ashley Fisher

Interestingly, this is roughly how you tape an ankle to prevent ankle sprains in sports medicine. That's basically a reusable taped ankle. And they just sort of keep your...


Kasi
This part's hard. So It doesn't allow me to It's prevents me from hyper extending my wrist. that's mostly what the purpose of...


Teagan
our joints. So my.. most of her fingers hyper extend. mine don't too much except for like, these joints here. But luckily these don't Yeah.


Ashley Fisher
Yeah. Okay.


Teagan
She's getting ring braces to help with that? They have to be custom-made for your fingers, right. But Yeah, my problem tends to be with this thumb? Yeah. Check. That one. So that brace can actually help by relaxing These muscles. Okay, so that way, if this one gets offered up, There are ones that you can get specifically, but to know, Yeah, I tend to not use those because I find them annoying. But I am potentially going to get a ring brace for this particular joint, I do find that I have a problem of when I work. I'll just go like this. And that. OK.


Kasi
Especially my wrist. Sometimes by choice, but because mostly because the thing with my wrists is I paint and draw a lot. So It's a lot of this kind of thing or holding weird positions with this giant canvas. And that very quickly will hurt my wrist. These things like Oh, I need to do like a thing. It's like my hand. Well, yeah. Okay. And I get oil paint on it. And I like... oh... that later. Yeah.


Teagan
I, judging by the amount of walking we're going to do also really depends on what shoes I will wear. Because I have a very heavy duty pair of shoes, which provide some support – the insoles naturally provide support to your arches. Okay, So I have that in the sense that this joint on my right foot subluxes a lot. So if we do a lot of walking, even though I love wearing sandals, But also, because the connexion in my feet are so loose,  Here And here will slide out of place. And that's not very comfortable.


Ashley Fisher
Oh, no, I can't imagine.


Teagan
I'm actually gonna see an orthopedic person about that.


Kasi
I don't have those problems per se. I can't wear flip flops, because my skin is very sensitive.


Teagan

That's another [EDS thing.]

Kasi
Yeah. It's also possible I just have baby skin. My shoes are high tops. the ones that go..
Yeah, Yeah, they go up to the ankle. I don't think I'm actually having problems with my ankle.

Teagan
It could actually be subluxing your ankle. But if you're only loosening it up right to the middle
of your ankle, You can actually start pushing them apart because of how you lace it.

Ashley Fisher
So they lace it up all the way

Kasi
I do.

Teagan
But You also need to make sure you don't get too tight or otherwise.

Kasi
That will rub my ankle off. So I have to wear socks that go past where it is because I will rub
my skin raw. So supports in there, which are going to make sure I don't get flat footed. But
will also attempt to make a pain in my hips go away. They were.. also apparently one of my
legs is just like, tiny bit shorter than the other. But I don't think that was addressed in that. So
I

Ashley Fisher
Just stick an extra couple of tissues.

Kasi
My shoes aren't tight.

Ashley Fisher
So it's finding the right balance between too tight and too loose.

Kasi
Yeah, because I have to wear shoe sizes that are bigger than mine. Any pressure on my
feet. So I have to wear something that fits but it has to be enough enough so there's no
pressure on my feet. Because that will it will just make my feet ache. Alright. I'm think I'm
what size seven? Yeah.

Ashley Fisher
That's pretty small feet given your height.

Kasi

So I don't really have much of a I don't have as many problems as Teagan does with feet. But like, sometimes my knee will just give out. It's not like it slips like Teagan's does, like a nerve pinches or something. Or might have

Teagan
Some nerve tissue

Kasi
Yeah, it just can't put pressure on it's very painful.

Teagan
But it tends to be something you just kind of have to do the wrong way, you sit down. But it's variable about time for how long it'll take to rebound.

Kasi
I do know that. Like if I just like oh, I'll just push through it. no it just gets worse. Yeah, You can't push.

Teagan
You know, something we've been considering is looking into buying some mobility aids. It doesn't, it doesn't happen often enough for me to found it worth it to own a cane. I've used to have one when I lived in the States. I didn't need a very often so I didn't think it was worth it to come here. But my right hip gives me trouble sometimes. The other problem with all of that stuff I found is just especially like our mom, who has not been diagnosed, likely has EDS Also, She got a number of slip discs and her back, which caused her mobility to decrease significantly. So One of the things that we really needed to get for her was a cane that has a seat on it. But they're all aimed at really really old people. So you get one custom made. Yeah. Yeah. And So trying to get one that would look nice. But have both functions. It's quite difficult. But If I do go the route of getting a cane, probably end up being one of those. But that will something I purchase in the next 5 years.

Kasi
Another thing, Like all the leg get swollen, and like skin becomes really sensitive to your clothes

Teagan
Still have to be because of the EDS. You're thinking of combination of things that's likely could also be POTS but from the is what the heat rush when you get this swelling in your hands and stuff tends to be quite a time.

Kasi
Whatever The leg thing is, if I walk too fast, My legs will start to become like inflamed. And it's like it's like the rubbing raw thing again, like with my pants, it can be in tights, it can be shorts, It was just my skin. heated and marbling. My, I think I have part of it. It's the connective tissue in my veins, more like that. blood flow is bad. So If I'm walking too fast, It means like, it's having trouble. It's like pulling my leg or something I don't know. Sorry. Like they become like, essentially swollen and like hot. And it can be hard to move especially because my hands have been hurting. And I do have trouble with my hands which a small friend of mine For a while, but it was connected to being dehydrated, which it kind of is but it also just happens. My fingers will swell to the point I can't close my hand.

Teagan

Yeah, I found that happens more often with heat. But there is not actually a correlation that I find just as likely to happen during the summer as it is in the winter.


Kasi

Yeah, I thought it had to do with touching metal. I thought I was allergic metal for a while. But it will just happen. randomise. See, my thing is like I was at the bookstore a week ago. For some reason, my right  hand completely swelled up. I had just been standing there like I have my hands down. I have a trouble. I think it's the whole blood flow thing again, my arms will start turning now. And then my hand swelled up. Like That's weird. Okay, just can't hold a book now in this hand. So weird.


Teagan

so awkward, especially if you're walking by yourself. And just like I awkwardly, just like keep on adjusting my collar.


Kasi

I feel like the circulation cut off under my arms. So I'll tend to slow it. but then I run the risk of Over extending my shoulder. Yeah.


Ashley Fisher

So we've gone through Kasi's morning routine. Now you get to take me through. I need to find out the stuff that has to do with Annora to because this is temporary accessibility issue.


Teagan

So I can just going to say... Okay, fantastic. So basically what happens is Annora wakes up some ungodly hour I grab her and I feed her. And normally she goes back to sleep, She will then wake up sometime between 630 and 730 and decided she  no longer wants to go back to sleep. I am quite slow to wake up in the morning because I tend to need to allow my blood flow to normalise. Because If I go from a heavy sleep to suddenly standing up very quickly, My blood has not reached my brain yet. And I can black out. So I need a few minutes to just become alive. So What will typically happen is Brennen will take her and do the first morning change. he'll either get her into the day's outfit, or he'll bring her back in here to get the days out. And then I will go and I will get dressed After checking the weather to see like what temperature it is. Because the poor circulation that I have, I tend to get cold Very, very easily. So I always tend to dress warmer, sometimes even warmer than I dress my baby Because I don't want to overheat her. She gets very cranky if she gets too hot, and she's... And then we will go downstairs and I will start getting everyone ready to eat she tends to eat Weetabix. For breakfast. I have a hard time with breakfast because that tends to be where my digestion is the most picky. And I think it's because it emptied out. And So now it's putting stuff on to a. So I tend to try and avoid wheat in the morning, just as a general thing. So What I typically have is coconut yoghurt. Because I can't have dairy right now with Annora because she's lactose intolerant. So it's So it's yoghurt, made with coconut milk, instead of cow's milk. Mixed with frozen berries, almond flakes, cinnamon, and sesame seed, sesame seeds. And occasionally raisins and peanut butter, nice little protein boost. And then we try and make sure that we're completely ready before we get her ready because she tends to get fussy. So while one of us is feeding her, The other one typically then goes and make sure that her pack is fully stocked. Technically, I restock at the end of the day. So that way I know like immediately what I need to do, I try to check. Before we go out to just to make sure that I haven't forgot to get back to like diapers, You have to make

sure we have enough diapers to make sure that the wipes are existed. If I'm running low to put a second one of those, She needs at least two changes clothing. Because baby, And you never know. And then she also needs some burp rags. She's old enough now that she doesn't really spit up very much. She still she really likes to try and feed herself but she does not have the coordination to feed herself. So we do need the ability to clean ourselves up, should anything happen. And then I also try and make sure that there are snacks and stuff for her. If I am exceptionally forward thinking I will try and put a snack on myself. However, that requires me of forward thinking when I was shopping. So that doesn't happen as often as it does, it tends to me that I tend to buy more specs at the place Because I don't often have problems for blood sugar. But every once in a while I'll just if my blood pressure drops too much then eating something will balance it out. I'm trying to put like one toy in there- she tends to get just like people watching so she doesn't really need a toy. But sometimes it's nice to distract her while we're waiting for food to show up. And that she basically just needs socks, shoes, trousers, shirt, And some kind of hat or a cap. Too much Really cool for anyone. And then if my husband is coming with us, We will bring the baby carrier she's now too heavy for me to carry in the baby carrier. So I take her in the push chair everywhere We have nice jogging pushchair so that way I could take a nice full steps and not need to worry about me kicking and potentially damaging my feet trying to push the stroller. And then also I don't have a tonne of vibrations, killing my joints

Kasi
Oh yeah the carts, the shopping carts can my hand swell up very fast you

Teagan
I love the carts in this country they so much nicer than they are in America.  I don't know why. people take care of their carts better? And then I will then check public transportation on the phone. Since the six is right there. I have the first app on my phone so I can see When they're coming, I'm going to try and leave the house where they are within five minutes of appearing. And then we'll leave otherwise we'll just like kill time, distract her.

Ashley Fisher
Excellent. That's all I have for this time. Do you guys have any questions about this? Anything else you want to mention?

Kasi
You're gonna be talking to us? Or are you just going to be silently stalking us?

Ashley Fisher
We'll see how the day goes. For the trip I'm planning on being side by side with you, not standing back and watching. I will be taking notes every now and then. Good job. Don't let that intimidate you. Because it might just be something that caught my eye and it was really cool. And I want to do it somewhere else. For the visit itself, you guys are going to be leading it, there's a couple things I want to make sure that we hit. There's one exhibition that I want to make sure we go to the same exhibition, so that everyone is going to be having a point of comparison. We're going to check the toilets, which obviously won't be a problem Now. Okay, and I want you to ask for help  from a staff member.

## 8.2. Site Visit.

I met Kasi and Teagan at Teagan's home, then journeyed with them to Abbey House Museum and back. This trip took place on 2 June, 2019.

[all three of us pay admission, the staff member then directs us to a gate to the side of the entrace corridor

Staff member
[On radio] Three headed your way.


[we're let in the accessible way, which avoids two stairs and takes us straight into the Victorian Street exhibition]


Ashley Fisher
Thank you.


Staff member
Just to give you a few more tips like that [she gives us a bit of an overview about the gallery, and lets us know that if we have any questions, feel free to ask her].


-


Teagan
[suggestion we go to the café] Wait there for 30 minutes and then... dragging. 'Cause she's not really settling.


Ashley Fisher
[sounds of us making our way to the front of the exhibition]


Teagan
If we pop into the café and we come back and...?


Staff member
You can come in as many times as you like during the day. We just have a cutoff point. I'll just be a moment.


Ashley Fisher
So what do you think of the museum so far?


Kasi
It's interesting. That it's displayed like a street. I wasn't expecting that. You were right about it having nothing to do with the Abbey.


Ashley Fisher
Absolutely nothing.


Kasi

I wish they had the labels of things . Okay. Yes. Just because I don't know what a lot of things are. But that might just be because I'm American.

Ashley Fisher
I think a lot of people coming here don't know what a lot of these things are. Okay.

Kasi
And it's great if they have someone talking, but there's only one. And if theres a bunch of people.

Ashley Fisher
And clearly there's at least two groups in there right now. So us and that other groups,

Kasi
so it seems like that could be a stressful job. Yes, yes. Okay.

Ashley Fisher
No, I think you're... I think they rely very heavily on the person in that room to provide the interpretation. Yeah. Which is, has its strengths and weaknesses.

Kasi
Yeah, I mean, it's okay. If it was like, more than one. Yeah.

Ashley Fisher
Yeah. Would you feel comfortable going and asking her what something was?

Kasi
She was very nice. Okay, so yeah, I probably would be fine. Okay.

Ashley Fisher
That is like 75% of the battle, making sure that the room guides are approachable. Yeah.

-

Ashley Fisher
so finding the museum would you say it's easy to find from the street

Teagan
Yep.

Ashley Fisher
Was the signage easy to see?

Teagan
It was easy to see what tickets I'd need to get.

Ashley Fisher
Yep.  Was it easy to find the entrance?

Teagan
Well I almost went to the café but then I saw there were steps and stuff, so I was like "ahh... that's where I need to go."

Ashley Fisher
Were there any barriers to getting inside like stairs, heavy doors?


[a pause, no answer from Teagan or Kasi] I mean, the shop was a nightmare to get around but

Teagan
I didn't think it would be quite that bad. like if I had anything wider than that [points to the pushchair] I wouldn't be able to get around.

Kasi
I didn't realize the entrance to the area, that little gate thing. I thought  that it was a barrier.

Ashley Fisher
technically the actual entrance to that exhibition is a little- it's the one that she led us out of? So we miss the information table that explains some of the things.

Kasi
Yeah.

Teagan
Yeah. Because I think you have to go up some stairs.

Ashley Fisher
There's stairs, I think, to get to that point. Yeah. But why not just have everyone go that way? Anyway, it's things like this that aggravate me. The interactions with the staff so far. Yes.

Teagan
It was quite helpful. So yeah,

Ashley Fisher
I was asking Kasi we were talking about how there's not much written interpretation in that exhibit. So it's very reliant on the person that's in there. Would you feel comfortable asking that person asking her for information on the spot

Teagan
Yeah that lady's fine. She was quite personable.

Ashley Fisher
What do you think of that the Victorian street exhibition that we saw so far?

Teagan
It's quite similar to one that I saw at a Ren Faire [renaissance faire]. A pop up one that they had at [name of Ren Faire]

-

Ashley Fisher
Do you like that? It was a more immersive experience on that street?

Kasi
The street was cool. Yeah, the exhibits themselves didn't seem like they had a lot of room for the stuff they had set up there. Kitchen stuff is piled. Yeah. It's probably a lot more than a house.

Ashley Fisher
There's just too much.

Teagan
it was immersive on the other hand.

Ashley Fisher
So you like the immersive quality of it? It seemed like they might have volunteers. Just by the setup and what I know at the castle museum it seemed like they might have volunteers that come in and you know man a shop.

Kasi
Yeah, that'd be cool.

Ashley Fisher
Yeah. I know the Castle Museum does and it's very cool

Teagan
I liked the dress up stuff, except when someone's fussy [referring to the baby].

Ashley Fisher
I saw you guys flipping through the little haberdashery booklet. Were you reading it? Were you just looking at the pictures?

Kasi
I was looking at pictures. It was also noticing it was really hard to go through.

Ashley Fisher
Okay.

Kasi
Especially if you had one hand there's no yeah. We didn't bother reading the font it's kind of difficult.

Ashley Fisher
Fair enough. Yeah.

Teagan
I mean, it was convenient but uh.. but I would have rather been able to like go sit down or something like that. But I would have actually read it if I could sat down, yeah.

Ashley Fisher
I didn't notice any seating areas in that first section. At least

Teagan
there is in the haberdashery for that

Ashley Fisher
Yeah, there was a bench in there. I mean, there were the toilet seats that second street

Teagan
Yeah, I suppose you could sit on those.

Ashley Fisher
but I'm not sure you don't want to. Whenever I'm in exhibitions like that, it always feels to me like they're just trying to put as many objects from their storage on display as possible and not really caring whether or not people understand what they are that's always what it seems like some it's just a lot of clutter and it's not very clear to me if that's how it was or that's just them trying to display a whole bunch of really cool objects.

Teagan
I just assumed it was cool.

Kasi
Teagan, do you remember going to the King Tut museum? I thought that some of that was laid out pretty well. But it was a portable museum so they had to didn't have too much stuff. It was divided in like districts, this district is this section is the- biggest the one that was like the sex district.

Ashley Fisher
Oh, okay.

Kasi
Interesting bits of art there.

Teagan
It wasn't King Tut, it was Pompeii. It was- Yeah, it was the Pompeii exhibition. They had a travelling Pompeii exhibit close to the Getty [a museum in America] so that's probably that.

Ashley Fisher
What did you think of the layout of that? Victorian street?

Teagan
There was two steps to have actually get into the exhibit so it was completely stuff that we're accessing where to get back into where the seating area was. Yeah.

Kasi
I was kind of confused where we moved on. Yeah, so that was through the stores and that was like it. Which I mean granted it was authentic to the Victorian era.

Teagan
Authenticity versus accessibility.

Ashley Fisher
Yeah. Do you think it was too dark or too light in that area.

Kasi
It was a bit dark

Teagan
the lighting was fine except for when they added additional light it was too bright. Okay, because then made everything else seems darker because you suddenly don't...

Ashley Fisher
You realize you had the con[trast].

Teagan
OK, so the lighting needs to be angled differently so that way you don't look directly into it.

Ashley Fisher
Yeah, that makes everything else.... yeah,

Teagan
yeah. So I think they just need to angle the lights differently.

Kasi
Yeah, like you walked in, turned around immediately blinded.

Ashley Fisher
Well, even walking out there was no way to avoid looking at least almost into that spotlight.

Teagan
Which is not good when you add it to that step.


Kasi
And the computer thing didn't work


Ashley Fisher
The computer thing didn't work. It wasn't clear how it was supposed to work.


Kasi
I tried swiping left nothing happened – yeah nothing happened. Did it really exaggerated?
And then it delayed it, slowly Yeah.


Ashley Fisher
When we have our café chat I have a worksheet for you guys as a simplified version of all
these questions. Because you don't need to answer every single one of them.


for level access to the museum. Yeah. Oooo who wants stickers? Everybody wants stickers.
Excellent. And one for [baby] too!


Ashley Fisher
so lighting in here do you think it's been ok?


Teagan
The lighting in this whole pub is better.


Ashley Fisher
Ok.


Teagan
Because the lights are covered Yes. So you're not staring directly into them.


Ashley Fisher
They're there. diffusing the light better.


Kasi
[reading aloud] gross, grocer... "Refrigeration before people have..." it's a bit hard to read.
Yeah, little hard to read. "Before they had freezers, they found it more difficult to store of
fresh food for a length of time and so had to make many more trips to their local grocer.
refrigeration is the process of removing from an enclosed space or from a..." [baby takes
booklet from her] I guess I'm done with that. Does say [unintelligble].


-


[in the Danger Zone xhibition]

Kasi
dangers in  a kitchen. more than large number of children experience an accident in the kitchen. Kitchen Cabinets. I don't know what those symbols-  we can something with

Teagan
the numbers correspond with

Kasi
no no, I mean the hazard sign –  it looks like explosion fire bubble

Ashley Fisher
No, I don't see a key anywhere.

Teagan
[points out the key at the beginning of the exhibition]

Ashley Fisher
And it's covered up by the machine

Kasi
flammable. It was boiling liquid and something else that's covered up.

Ashley Fisher
Also a key above that. [points to a beam in the ceiling] But again, super helpful to have them like over there.

-

Kasi
Yeah, I mean, I have trouble keeping in line. Okay, so if I can't put my finger against it, it's hard to that sometimes just skip lines. Sure. So the glass is kind of hard to

Ashley Fisher
Yeah. I noticed that they had physical lines between the things [entries on the sign] – does that help, it all

Kasi
It doesn't always. Okay, because it's like, it's like the line paragraph. If I accidentally switched another line, that line is still underneath. So you keep your fingers there so you can track it. Okay.

Ashley Fisher
How's the lighting here?

Kasi
is good.

Ashley Fisher
Yeah. Where are the stories that they're telling in the cases easy to understand?

Kasi
No. Okay. It was like, especially that I didn't know what was bashed against what like what's the kibosh his head against the thing? Did they grab the monkey?

Ashley Fisher
Yeah.

Kasi
And I wish the sign – Like what do these signs mean?

Ashley Fisher
the key should have been put elsewhere?

Kasi
Yeah.

Teagan
And the way  that the things were shown inside the exhibit. It was hard to read the, you know, the top part that I was supposed to like?

Kasi
Yes. Yeah. And especially because they have a little number of things when something like the monkey were was on a chair and there was a monkey they had

Ashley Fisher
the tickets, right next year six. Yeah, so which, yeah.

Teagan
I know I just rested in the kids area but I'm still tired

Kasi
Thanks she can take a nap.

Teagan
She was disappointed with the lack of things to do.

-

Ashley Fisher
[alarm in the accessible toilet goes off, staff member handles it quickly and professionally – it's just a false alarm] there's a reset button on the left hand side.

## 8.3. Post-Visit Interview.

Our post-visit interview took place at a pub down the road from Abbey House. Due to the wind in the area as well as over-head planes, the audio is difficult to understand and I was unable to transcribe it.

## 8.4. Follow-up Interview.

We met at a café for this interview on 5 June, 2019.

Ashley Fisher
Right, so going back over our recordings earlier today, actually I can hear things so that's a good start. I'm just repeating a couple things. If you guys have one thing to say to the museum, what would it be? Teagan, you had said sounds, make some kind of sounds, make some kind of noises and Kasi you had said they need more space to do you guys still agree with those.

Kasi
Yep.

Teagan
Yep.

Ashley Fisher
Okay. And your favourite things were- Teagan, it was the he/she/them exhibition, and for Kasi, it was the Victorian Street.

Kasi
Yep. Still agreeing with that. Yeah,

Teagan
yeah, primarily because I had Annora with me. If I hadn't had Annora with me. Then I probably would have enjoyed the Victorian street more. But I have been on Victorian streets before so it wasn't quite the same. I do always enjoy them.

Kasi
I just like the fact that they made a street in a building. That made me happy.

Ashley Fisher
Right, so you also said that you likely wouldn't return alone, or immediately, but it might be a place for you guys to take someone that hadn't been. Still agree with that?

Teagan
Yeah.

Ashley Fisher
Now why do you think that

Teagan
because of how far away it is.

Kasi
Oh yeah. And like it was good. But it didn't have enough stuff to feel like I saw everything. So like, I wouldn't be oh man I didn't I didn't get to see this or I really want to pay more attention then go back over this. Like, yeah I saw it, saw everything.

Ashley Fisher
For getting there, do you think the museum could help, could help with information? Could they help clarify things? Make the whole experience easier?

Teagan
No, I think it was about as painless as it could be.

Kasi
So how did you feel the next day.

Teagan
Tired for the rest of the day.

Kasi
I fell asleep immediately. Brennen was like What did she do to you guys.

Teagan
He was so confused.

Kasi
What time do we get home.

Teagan
We put Annora to bed about an hour early so would have been about 430 or five.

Kasi
I went to bed at the same time as Annora. I was really tired.

Ashley Fisher
I got home, at about five o'clock and I'm just laid down and in bed for an hour and a half. It was a very long day, very long day. Yeah, but did you have any problems the next day – because I know you guys say that you do need to make sure you're taking easy otherwise you have repercussions.

Teagan
I was quite sore the next day.

Kasi

I think I was. Having a hard time remembering

Teagan
you went to London. The next day,

-

Teagan
Anyway, to actual question. I would say I probably had an uptick in pain level by about one or two. The next day. Yeah, cuz I had to wear my wrist braces at work.

Kasi
I don't do that.

Teagan
I had to wear both braces this time because both wrists hurt.

Ashley Fisher
I know I had shin splints basically all of Monday.

Teagan
That was probably just from walking so quickly to get to the train. We started the day out great. With a nice little relaxing break on the train, which was good.

Kasi
I was like pouring sweat but it was fine.

Teagan
I feel for the man that was sitting in the other seat with us.

Ashley Fisher
We were going around the museum and that may reiterate this is definitely a question you can say no I don't want to answer. Do you feel like your EDS or your dyslexia affected your experience more

Kasi
dyslexia. Yeah.

Teagan
You probably noticed by how little time we spent staring at each thing.

Kasi
We would look at that thing another label. It's why we spent more time, I think, in the street than we did in the danger zone, because the danger zone required a lot of reading, and it was. And it was hard was very difficult to match the things you look down at the number and you look at the thing and then you forget which one you were looking at and you go, oh and

then you just... just gave up because it wasn't worth it. So I guess we're just going to go into the next thing.

Teagan
And put her in a bunch of 10 p things. And then get a bunch of old pennies and then contemplate as to whether or not you should. You get to keep them.

Kasi
How would you compare them use this museum experience at every house with other museums you've been to.

Teagan
I would say it's on par in terms of how much you have to read, it's actually quite similar to most museums. Yeah, I would definitely say it's in terms of reading it was quite similar. Because it's just a problem that most museums have.

Kasi
I feel like it was a bit more... I don't want to say disorganised but cluttered. I think, again, I think it was a space problem of the fact that danger zone. Yeah, and the space it was a non permanent exhibit so there wasn't as much as thought and placement because it wasn't permanent.

Ashley Fisher
How would you have museums, fix the reading issue, like with this text. I showed you that Claro scan pen app thing. So, do you think double checking all texts against that helpful wouldn't have been helpful in the danger zone.

Teagan
No that was very disorganised, the way that the danger zone could have done that though is if it had a little integrated thing. So you can see spotlights so light will shine on the thing. Once you once you looked at them. That way you could.

Ashley Fisher
That doesn't even have to be a very high tech thing it's a simple lighting rig.

Kasi
I think part of it also is my first question whatever I look at is, what is it, and what is it, what is it for. And then what about it, but usually The written text is where did it come from. And it's like, I was looking at the room with all the pots and pans I think something very good to have is visual contexts like set it up how it will be in that time that's extremely helpful, because then I don't have to read. Is this a bathroom is this the kitchen. That helps a lot and just being a just having the main points about it. I think it's also good because my biggest complaint with the danger zone is my other complaint is the context. I didn't know what the context of the objects were in relation to what it could be.

And the facts given... yeah, like the monkey. The monkey didn't make sense that reading the text was about the monkey, wasn't about the monkey, it was about someone who bought the monkey. And I was like, well, that's not that's not really the story of the monkey you can have

the story is fine but I'd like to know what it is, what it was for, and then the history behind it. I feel like that would be helpful.

Teagan
Yeah, I mean you could do that really simply just by having like printout background of, you know, yeah just have a little kids room or a kitchen or something. Something like that. But that would have been a space issue because that would have expanded the amount of size that they had and

Kasi
I really like the light solution. And maybe just.

Teagan
And I find the museum's that have little push button things, helpful. I've only seen that something done like that in one or two times, it's always, at technology museums. I've never seen them at something that wasn't a Technology Museum.

Kasi
I think what I think about when I look at how I look at the exhibition, I look at it, try to figure out what it is by looking at it find its name, and then try to figure out more about it because reading that giant block of text just know I don't get as much as visualising it. I don't remember where it was, but I think it was a car museum. They had the objects and their name, but next to it, they'd have pictures of people using it. So you could really see them using that with archaeological things but like showing how this rq this object is used. So I giving it more context so like, just reading someone did something with it isn't always as clear,

Teagan
Something that I think that could have been really cool with the danger zone is granted this would cost a bit more money. But like, even if they had like a TV next to it. So you could just see how this object was used, like the child swing for example the dangerous one you could see, you could click on it and like a little cartoon would pop up with a kid in it and it goes all wrong. Oh no, because it's the danger zone, little cartoon thing, kind of like

Kasi
Like the Fallout, the Fallout game, animation. Like it's friendly but it's.

Ashley Fisher
I mean, remember the, the pictures that at the end they showed, and all these different accidents with people and cars, and like children things children used.

Teagan
Luckily my child was distracted by books and taking them out of a box repeatedly.

Ashley Fisher
Do you think that there's a difference in your experience at paying museums versus non paying museums? Obviously this was a paying museum.

Kasi
Gonna have to ask you on that one.


Teagan
I think you expect slightly more if you pay and the amount that you pay scales. But I wouldn't say too terribly much. But I think that's partially because we're from a place where all museums charge.


Ashley Fisher
Yeah, I was gonna say might be a very cultural thing because British people have a lot more feelings about paying for museums, but I can't think of any free museums that I ever went to back in the States, and that includes the tiny little County Museum, that had two rooms.


Kasi
They charge at the Singer museum and I think that's a room.


Teagan
Yeah.


Ashley Fisher
What if we had gone on a bad day with your EDS? How do you think they would have changed things.


Kasi
I would have sat down a lot more frequently a lot more often. I probably wouldn't have looked at as much stuff that wasn't in your chairs. I've had days where I've gone to museums and it's just not...


Teagan
I mean you could tell by, you could tell how tired I was by the end of it. Like, it wasn't necessarily my joint pain. Although my joint pain was starting to uptick, but that was just because daughter was requiring to be held all the time. By only me. I think her bottom tooth is coming through. But yeah, I was starting to get really, really exhausted towards the end, just why I not only sat down with Annora, to let her play with the blocks with the books, but then also I went into the shoe and we just died for a moment.


Kasi
And a nap happened.


Teagan
So, in that sense I thought it was placed perfectly, because I got, I was getting tired. Just as there was more things that I could do while sitting down, that we're also kids differently, although granted that house in the shoe could have been used by shoe could have been used by anyone.


Ashley Fisher
That is for sure.

Kasi
I know I'm less likely to read if I'm tired because it's very mentally exhausting. So when I'm physically exhausted. I'm fine. I'll just look at it, just a cool thing to look at me I think I asked you what something was more that I read.

Ashley Fisher
There were quite a few times, especially in the Victorians, and you're asking me and I'm going. I was listening back in this, there's there's literally a lady that said, we could ask her questions that we kept saying how approachable she was and yet we never approached her.

Kasi
She approached me and I asked her a question while she was there, you were there.

Teagan
I think that's more Kasi's personality. She will literally start asking questions of whoever's standing there just whoever is literally right next to her and her curiosity. It's not as strong enough to actually go up and ask, ask someone once she's left the particular area.

Ashley Fisher
Like you said, correct me if I'm wrong but that you might have- that you have ADHD.

Kasi
Yeah, yeah so that's probably part of it.

Ashley Fisher
Yeah, probably just from my experience with kids with ADHD they ask a question, and if you don't ask and if you don't answer it within half a second, they don't care anymore.

-

Ashley Fisher
This is a great transition because it's probably my most invasive question of the entire process. Do you consider yourself disabled. And again, I want to reiterate, you can tell me. No, I don't. I'm not answering this question.

Teagan
I consider myself as someone who has a disability but not that I'm disabled, mainly because it's, in my mind, not severe enough to warrant me needing to buy what are those seats or keys for the disabled toilets or constantly needing a mobility aid for me to constantly... to make significant changes in my work or accommodations or stuff like that but it does affect. To me, I'm to the point that I would say I have a disability.

Kasi
I would agree, just specifically because I wouldn't even really say I'm physically disabled in my mind that would mean, I mean I get tired and I can't do certain things for long. But like I don't need a disabled toilet. I don't need a wheelchair. And because I don't directly need those things. I feel like that belongs to someone else. I don't know. And the only thing I say

that actively impacts me a lot, would be dyslexia, but usually I can get by fine with someone knowing that, Like, I don't need special help, don't really need special accommodations.

Teagan
We definitely needed it in uni, in academia.

Kasi
And when it comes to work it's usually just my boss understanding that I'm a bit slower. When it comes to reading things, and that there will usually be some kind of spelling errors, but other than that it's not, it's not too bad.

Teagan
So, I was actually having this exact same conversation with Brennen not too long ago. Yeah. My suspicion is partially, the conditioning that we've received, of what a stereotype of someone with a disability is. And I think, Kasi and I both accept the fact that at some point in our lives will be disabled. And when we're older, there is a strong possibility that we will need a wheelchair to get around and that kind of stuff.

Kasi
Which would happen hopefully not for a significant amount of time, not until our 80s.

Teagan
But we are able to have a mother as a good example now my mother is did not take care of her body at all. She. She was a, she was a ballerina dancer for quite a long time. In a Polynesian dancer. So she was always quite fit. But my father has had to basically paid to fix her body so many times, and I can't think of one vacation or anything that we ever took on that mom wasn't in pain for. And it was always kind of an undercurrent of her having to take some kind of painkiller or, or her making a paint noise. Oh, no. No, I'm fine let's carry on. I'm just gonna sit for a bit you guys come back and find me. Don't worry about me go have fun, that type of stuff.

Kasi
Yeah, I mean, I think part of it was me so I definitely. I've accepted this is probably the best I'm ever going to feel or be in my mind, so I could probably, I could probably more physically fit but I don't think that kind of pains ever was going away I don't think my dyslexia ever is is ever going to go away. And I don't think not know but in the future. it's definitely going to be a regression of who I am and that makes me sad. But I wouldn't say I'm at a point where I'm unlucky. If that makes sense. I don't know. I also think that probably, in my mind, it's been stigmatised that I wouldn't call myself disabled, because I'm not severely mentally, physically disabled so it's like, I can get on roller coasters, I can graduate from college. So I just...

Ashley Fisher
Do you think it's somehow linked to independence?

Kasi
Well I think disabled people can be independent. I think someone in a wheelchair could, depending on how severe, could be independent. But it partially has to do with that and it more has to do with in my mind how much freedom. Like are you relying on someone else. Can you walk upstairs. Can you go into those kinds of things. Do you need to use one of

those Lift things or can you walk up the stairs. Like someone can be independent and we can use that Lift thing but can't go down the stairs.

Teagan
Yeah.

Ashley Fisher
Very interesting.

Teagan
I think it also has to do with the fact that it's kind of hard to judge, because everything becomes your new normal. As soon as you get used to it for long enough. So, someone may think, if they weren't chronic pain that that would then make them disabled. Kasi and I have chronic pain. And yet, even when we have like after I had Annora, I had an uptick in the amount of pain, chronic pain I had like on a scale of one to 10 they went up one as my new normal as my new constant, but I wouldn't say that it made me more disabled. Even though I will be able to say yes there was an obvious uptick.

Kasi
I think it's really interesting especially with hidden disabilities. I'm trying to think of this like with my friend, say if I was something like that, they sort of think I'm like, whatever with me Are you in pain right now. Yeah. And they're like, Oh, I didn't realise. I've never not in pain. I complain when it gets to the point where it's hard to deal with. It's like I wake up in pain, I go to sleep in pain right good little middle of the night with pain I sit down and pay night and pain.

Ashley Fisher
I am pain.

Kasi
I think like taking said it's the norm this pain is there. And it doesn't make me want to do things. But it doesn't make me not able to do things until it gets until it gets worse. And I don't know, I guess it's kind of this feeling of Can I push through. Could I keep going. Like with reading. It's really hard, but I can push through it, it's going to take me longer I'm gonna mess it up, someone's going to get very angry with me. But I can do it eventually I not everyone can and I think, to me, that's that barrier. That's the difference in disability versus disabled.

Ashley Fisher
Yeah.

Teagan
Like sometimes my husband, an able bodied man, he occasionally has pains in his legs that refuses to go to the doctor about. That's a different issue. But it doesn't quite understand though, when, why, want to do travelling, and that kind of stuff now I sees like Teagan we may not be able to. Should we save more money for the future, and that kind of stuff and like yeah that's fine and all, but why would I want to put off something that I may not be able to do in the future.

Kasi

I think with mom is a good example of that.


Teagan

Having our mother was a very good. It's a realistic expectation of what we may end up doing, which is one of the reasons why I've been so proactive in terms of physiotherapy and trying to prevent the uptake that I'm having with Annora, so that way I can try and manage it all.


Kasi

Yeah, cuz like when I think of what happens to my mom and what could happen to me. I was very physically active as a kid but college kind of kicked that our mom kind of just hit a wall like a brick wall, and then it just that was it. That's pretty much it dead stop, and then fall.


Teagan

She's quite in denial about it too for quite a while. Take it.


Kasi

How many times have had to yell at her to not pick things up like the day after her surgery. When she got those shots, she got like shots. You're not supposed to do anything when you get those shots because otherwise it will immediately reverse it, and she was like, I feel better I could do it. No, you feel better because you're not hurting yourself. Like, I know feel okay, doing certain things, but if I'm an idiot and I do things more exaggerated things than like I can feel okay, I could do things I never would do normally but what I could go run a mile and then fall back, and then die and dislocated dislocate my knee as I stepped out wrong. I know I still have a problem, even though don't feel it as bad as other times, if I don't keep that in mind, other times are going to be all the time. I know if I sit crisscross applesauce relax my legs. Relax My knees and lean forward I will dislocate my kneecap so I don't do that anymore. And it hasn't happened in years. Doesn't mean I'm going to do it. It's kind of like being allergic to food. My mom's started eat more food that she's allergic to 'I didn't have reactions!!!!'


Ashley Fisher

I think it makes a very interesting point about the difference between your mom and you guys though, because you've grown up, mostly grown up with these diagnoses and she hasn't.


Teagan

I mean if I didn't have Teagan. I think I'd much more like her and I think I would have ruined my body way more than I have much more like your mother You mean yeah because one thing that I made sure to do. Whenever I went to physiotherapy whenever I learned about something I then told Kasi about it, so she had kind of a five years advantage, a lot of the stuff.


Kasi

Did I take it? Questionable.


Teagan

But she did have that knowledge seeping into her and work, it's a lot of constantly telling her to avoid doing this because this can exaggerate it and that kind of stuff. Granted, I was wasn't able to help her with reading anything like that.

Kasi
It's funny because you were blamed for some of it. Some of my. Some of my teachers thought she taught me how to be dyslexic

Ashley Fisher
That's not how dyslexia works....

Kasi
I thought it was so funny that you that that you, you got certain letters right and I got them wrong and take its pattern. Oh well. What can I say... I don't know if I ever told you that I remember that very vividly.

Teagan
I'm sure you have.

Kasi
I think it was the, the letters and numbers ones. Yeah. I don't tend to mix up letters and numbers. No. Yeah, I do. I make mix up nines and fours though.

Teagan
That's why when I make my nines of my fours, they're very distinct when I write them. The way I wrote my letters is distinct so that I know

Kasi
I absolutely thought about that with my handwriting too.

Teagan
Yeah, cuz my sister and I have almost identical handwriting actually looking at sheets yeah I could see that that sure they were more identical early on yeah they're quite similar.

Kasi
She's better at cursive. We write our Es almost exactly the same in my opinion.

Teagan
But just in general we tend to write Es the same way.

Kasi
But, especially with.

Teagan
That's why when I wrote my thank you cards, my wedding, I conscripted my sister to help me write them.

Kasi
Yep, yep.

Teagan
No one knew the difference. Nope.

Kasi
Well, that's the end of my questions for this you guys have any questions or anything. Anything you want to talk about now.

Teagan
I hope this was useful.

Ashley Fisher
It was shockingly useful actually. Yeah. Like, I feel I could write an entire thesis just on you two  so. So this is very very helpful. There were a couple things that I wanted to double check. Kasi I need your email address because the one.

## 8.5. Barley Hall follow-up.

- Changes
  - o Didn't cater to kids anymore – especially the upper level
  - o Flow of ground floor worked
  - o Not missing anything in closed off areas
  - o Lighting in lower chamber WAY too low
- Map
  - o Boxes on map – font/colouring was a bit hard to go between black on white and then white on black
- Sudden turns are hard on the hips – but removing the table would make people pass right through
  - o Angle the table a little?
- Liked the new front area – felt like you could stop and watch the film rather than sort of being in the way where it was before
- Height of the thresholds – mandated height?
  - o First two are VERY high
  - o Mitigate it somehow? Half step? Rope to hold on to?
- What's the point of the garden?
  - o Are the listed plants all there? Are they different plants?
  - o Rearranging heights if you want people to smell them – bending over is hard for some people
- Foyer
  - o Seems like a wasted area
  - o Light projection? Touch screen?
- Parlour
  - o Light was good – about as low as you should go
  - o "Cluttered by not cluttered" – good level of stuff in there
- But it did seem like they put the most stuff in the smallest rooms
- More magic on the tables in the Great Hall – spread the exhibition out a bit more
- Lesser Chamber
  - o Too dark for that amount of reading – especially with the objects

514

- Bit jarring entering the gift shop – going from nothing to everything
- Put the dreams bit in the parlour? Is the parlour meant to be magic or realistic?
- External handrail – too rough on one side, need to add one on the left side
- While we were there…
  - Sarah called reservations to handle an upgrade ticket – she had the agency to say "hey I don't know how to do this" and Paul allowed her to contact Res to learn how to do it
  - James had to turn away some walk-ins because of limited numbers; he explained the situation, that it was due to COVID restrictions, and they were very understanding and okay with it

## 8.6. Follow-up Interview.

I asked Teagan for her experience with sunflower lanyards. The notes from our conversation are as follows.
- Not a lot of change over all
- Sometimes gets looks, but is pretty sure that's more from people looking to see what's on her lanyard
- Scheme is helpful when you need to ask for help with a hidden disability
- Really questions when people say they get a lot of dirty looks for wearing the lanyard – influence of neurodiversity on the ability to read facial expressions?

# 9. Lisa.

Lisa is a woman with general anxiety disorder.

## 9.1. Pre-visit Interview.

I met Lisa at the Abbey House Museum and we sat in the attached café for this interview. We met on 20 November, 2019 in the morning.


Ashley Fisher
Excellent. So my name is Ashley, as you might have remembered, we've emailed a few times. And before we get started, I just wanted to go over a few things to make sure we're all on the same page. My research is looking at accessibility for people with hidden disabilities at museums and heritage sites and your participant because you have a disability. So, as mentioned, we'll have three different meetings one now, one, technically immediately after this. So to go around the site, and then later on, we'll probably schedule a Skype or a phone call or something like that. To have a follow up and talk about Basically, anything that's changed since then. So yes, I sent you, I think, a copy of the information sheet in the consent form, but I have copies here for you. So here's the Information sheets. And here's the consent form. We go much further. Get that out of the way. Fantastic and I might take some photos while we're here, but it's never going to be your face. I don't know if it's going to be like hands, things like that. Okay. Great. So I've got a few questions for you. Before we get started. You mentioned that you have anxiety I believe. Yes, yes. Okay. So obviously I've done a little research on it, but I want to hear your take on it, how you define it and how it impacts your daily life.


Lisa
So that's quite a good question. So I take medication. Anyway, it helps with that. So I take (setelopram?) and I've been on that now for about three years. And the way that impacts me mostly is sort of social anxiety. So it will be I can't just go out somewhere I have to kind of

think about how I look and think about how I'm going to get somewhere. Whether that's parking or buses, it's kind of planning to the extreme. Okay. So you know, other people might kind of look at the traffic route, but I would look at where can I stop? I would give lots of extra time to get somewhere. Either that or sometimes I'm mega late because I've had a panic attack so I'm either mega early or mega late. It means that I cancel my plans a lot. I don't always give the real reasons for cancelling. Okay, so you know I might tell my friends I'm really sorry and I know it was gonna come out for this has come up yeah. Or sometimes like it causes migraines, you know I have to cancel just because I'm just generally not feeling well. That's that's that's the main thing, really, social anxiety. I don't really go out that much. Yeah. Especially in the evening. And also because it's personally- so I had anxiety before my son was born but then after my son was born, so I have extra anxiety about different things. And so like, I don't like leaving him in the evening, we like routine. He's really good with routine. And I don't like to change that. So, you know, bedtime routine is very important in our house. So I won't just kind of leave him with a babysitter, Yeah, unless it's urgent. Yeah, so that's kind of how it works.

Ashley Fisher
Yeah, I take medication for anxiety as well. So a lot of what you were talking about with planning and sometimes cancelling and not always given the exact reason I do that. Yeah, just" Oh, I'm sorry. My daughter's not feeling very well, I think I better stay in." Yeah, it's, I understand completely. So talking about How you get ready for a trip to a museum or just anywhere in general? How do you prepare for it?

Lisa
So there will be a lot googling, okay? That would be where is it, Google where it is, so say I'm taking the car it'll be how long does it take to get there? How long would it normally take someone to get there then there's my added time. How long does it take me to get there? Yeah

Ashley Fisher
25% extra, Yeah,

Lisa
Yeah. Then it's where to park. So I use parkopedia quite a lot because it'll tell you the tariffs whether you pay by card or cash. I think about clothes. I don't like being too hot. So I have to think about what I'm gonna wear. Have I got enough change in my purse? like do I need to stop off at the petrol station? It will be. So sometimes I like to look for photographs of where I'm going, like the inside. So for example, if I didn't know this café, I'd be looking on Street View. Where's the door? How do I get in there? What's the menu like? So I haven't got an obsession with food. But if I'm going out for a meal, I would check what the menu is first before I get there. But we Yeah, like I say so looking inside what was the reception desks? So like I said, it's not planning to, to the extreme. Yeah. don't really need to do all that but that's what goes through my brain.

Ashley Fisher
I love looking on TripAdvisor just to see photos of menus. Yeah, I  would like but I just like to know. Yeah, yep. There were lots of little restaurants that we would go to quite a lot back in Chicago and I had a specific order every single time because I knew I could say it without stuttering. I knew exactly what the routine was. I couldn't deviate from it. Yeah,

Lisa

yeah. I went to a Thai restaurant with some friends for their birthday. And I had to look online and I was like, I can't pronounce anything. I don't know what these things are. So I just went with the Tikka Masala because I know I know what that is.

Ashley Fisher
Exactly. Yeah. Yeah, so lots of Google parkopedia? Yeah. Any other particular websites that you check?

Lisa
Probably Facebook. Okay. I'm on there quite a lot anyway. So I just find it handy sometimes to look at their pages. But nothing specific. It's normally just Google and I'll just see what comes up. Yeah. depends where I'm going

Ashley Fisher
Do you check out the museum's official website?

Lisa
Yep. Yeah. Yeah. And again, it might just be to see how many floors, where I should be heading, where they might recommend to park, because sometimes they have travel info on there so on. And sometimes just a general nose of things. Yeah.

Ashley Fisher
Do you ever check out accessibility pages?

Lisa
Not usually. It's normally on the same page. I wouldn't search it out. Sure.

Ashley Fisher
Okay, are there any specialist equipment or aids or things like that that you bring with you?

Lisa
No, just make sure that I've got my phone and it's fully charged and you know, day two and stuff. Yeah.

Ashley Fisher
What eventualities do you plan for?

Lisa
Oh crumbs. so there would be traffic jams. If it's public transport it would be so I need to get that bus. but if that bus cancels and I'm going to be late so I'll get there earlier but I tend to find.. sort of loo trips and something to eat. Sometimes I can feel a bit wobbly so like is there somewhere I can go back and just get a quick bite to eat and have a sit down. So, you know cafés and I'd like to know whether you know where the loos are. So I've been to places that don't have toilets and I hate that.

Ashley Fisher
Okay, how much time would you say it takes you to get everything together?

**Lisa**

Weeks. So I would normally as soon as I know I'm going somewhere, that's when I would start googling. Sure. And I would Google over and over again, even if it's the same information. Especially if I'm using Google Maps, I'll Google it and I'll be like, Okay, so how much time is it saying that it takes me at this time of day on and then it might be you know, the next week? I do on a different day, you know, how long is it going to be on this set? Because it changes Yeah. So for example, I went to Birmingham four weeks ago by myself which is quite a good thing. Yeah. And it said three hours and then the next morning and it said two hours. I still start off at the exact same time, just in case Yeah. I ended up having to just wait in the service station for ages to be late. Yeah, yeah, exactly. So yeah, it could take it. It's not that it takes me weeks of planning, it's just that that's when I start. Yeah.

**Ashley Fisher**

It's more that you do like a little bit each day.

**Lisa**

And it goes through my mind and I just think how many to look at that. Yeah. I mean, the Birmingham thing was quite funny because when it's for work, I can do it. And it doesn't bother me. But if I was going to Birmingham, from my trip for myself, I probably wouldn't even go to be honest, it's too much investment Yeah. Yeah. I've got a different hat on.

## 9.2. Site Visit.

Lisa and I then went around Abbey House Museum. This too was on 20 November, 2019. Sensing her rising anxiety, I did not audio record this part of our visit, instead taking more detailed notes.

## 9.3. Post-Visit Interview.

After the museum visit, Lisa and I walked down the road to a nearby pub. Again, this interview took place on 20 November, 2019.

**Ashley Fisher**

Okay, so let me pull up my questions. Yep. All right. Okay. Wonderful. So we've gone to Abbey House Museum. Now how would you normally get there?

**Lisa**

By car.

**Ashley Fisher**

And you know how to get there pretty?

**Lisa**

Yes.

**Ashley Fisher**

Pretty well by now. And when you're driving there, is it easy to find? Are there lots of signs along the road or...?

**Lisa**

No, I don't think there are, okay, and I know that people usually find.... have trouble finding the car park okay.


Ashley Fisher
So let's talk about finding a museum. Do you think it's easy to find the museum from the street itself?


Lisa
No, I don't think people know that it's there, actually, as a museum. They know there's a building now. Yeah, but...


Ashley Fisher
they don't realise that that's it.


Lisa
Yeah.


Ashley Fisher
Do you think the entrance is easy to find when you get up to the building?


Lisa
Depends which direction you come from, but I think it's okay. Although it's not clear, the sign kind of says that you can come in and there's a shop, but it's not really clear that that's the museum entrance.


Ashley Fisher
Right. Do you find the layout of the museum easy to understand?


Lisa
No, no.


Ashley Fisher
I like that you are being completely honest. You are not pulling any punches. So talking about the shop, do you find the signage easy to understand?


Lisa
No. I think it's quite difficult to know where you go from there.


Ashley Fisher
Okay.


Lisa
The pricing is clear. Yeah.


Ashley Fisher
Do you think there's enough space to move around the shop?

Lisa
Well, ideally, it would be bigger.

Ashley Fisher
Yeah, we're talking about an ideal world.

Lisa
It's okay if it was just me in the shop or just a couple people in the shop. If there had been a couple more people in the shop, I wouldn't have stopped.

Ashley Fisher
So I'd imagine if there's a school group there, oh, you're just hightailing it there.

Lisa
Yeah.

Ashley Fisher
Do you think it's easy to navigate the shop?

Lisa
Yeah. But there is a back bit that you might not know is there, where they have the books. You don't know it's there.

Ashley Fisher
No, no, I missed that.

Lisa
So right where the desk.. the desk's there, then there's a little door here and you can go in there and there's a load of books, but it's not clear that you are allowed to go. Yeah.

Ashley Fisher
Is it? I think I've been in that room before because it's like a big giant table.

Lisa
Yeah.

Ashley Fisher
I have been there before. But I completely forgot that it existed. Yeah. So turning to the toilets, were they easy to find?

Lisa
Yes, they are.

Ashley Fisher
Quite well signposted.

Lisa
Yeah.

Ashley Fisher
Were they clean?

Lisa
Yes.

Ashley Fisher
Was the floor especially clean?

Lisa
Yes, I think so.

Ashley Fisher
talking about the staff now. Did staff members treat you any differently than another visitor?

Lisa
No

Ashley Fisher
Was the team member able to offer help when you asked?

Lisa
Yes, yes. Very detailed help.

Ashley Fisher
Yeah. It was a good good spiel. Yeah. Did you feel welcome there?

Lisa
Yeah. Yeah.

Ashley Fisher
Do you think you would have felt welcome there if you weren't married to someone who worked there?

Lisa
Yeah, I do find this one of the friendlier museums I think probably because it's smaller. Yeah. And they, you are in touch with a lot of staff as you go through. Whereas other museums, you may only see one or two members of staff yeah

Ashley Fisher
seemed like there was a lot more staff there today than the last time I was here.

Lisa
That might be because they knew that they had the group in.

Ashley Fisher
Thinking about all of the exhibitions overall, were the displays clear. And you can interpret it however you want.

Lisa
I think the Victorian street has lots of little things that are not necessarily clearly signposted and you wouldn't know what they are. Okay. Unless you, you know, picked up some of the loose information. Yeah. I think they've done that on purpose. And I think the new ones upstairs are fairly well, like He/She/They and the danger zone. The signing, just quite engaging. As I mentioned, I don't look at the signs.

Ashley Fisher
Were there any videos that we watched? I don't think so.

Lisa
No there I did see some, but I didn't watch them.

Ashley Fisher
Were the stories and tales of the experiences easy to understand?

Lisa
Yeah, I think so. I would say so.

Ashley Fisher
How was the overall noise level?

Lisa
I'm generally quite good but as soon as the group's there, I'm not going in their direction. Even upstairs in the kids bit, so I love kids, but I wasn't going to be hanging around. And the end bit where the little girl was crawling. Yeah. I wasn't going to be trying to concentrate and look at the stuff, I'd just move through.

Ashley Fisher
yeah, it's gonna say you seem to move through that quite quick.

Lisa
Yeah, yeah.

Ashley Fisher
It's very polite. And you know, no one would notice. Do you think some places were too loud?

Lisa
For me? Yes. I think having that group there, it was quite loud.

Ashley Fisher
Any places that were too quiet?

Lisa
No.

Ashley Fisher
Now let's talk about lighting. How was the overall lighting?

Lisa
Good for me? Yeah. Cuz I mentioned I quite like... I quite like when it's not really bright artificial light. Tends to make me feel a bit wobbly. I mean it is quite dark in the Victorian street area, but I quite like that.

Ashley Fisher
Yeah. Were there any places that were too bright?

Lisa
The stairway going up was just quite bright. Yeah. But obviously I understand that it needs to be bright, right?

Ashley Fisher
Yeah. And do you think there any places that were too dark

Lisa
Not too dark for me. Okay.

Ashley Fisher
Was there enough places to sit or rest?

Lisa
No.

Ashley Fisher
Okay, so now we're going to think specifically about the Victorian streets. Yeah. You already mentioned that you think some of the displays weren't necessarily clear enough?

Lisa
Yeah.

Ashley Fisher
Were there any particular sections that popped out to you as you needed something a little bit more?

Lisa

The first one where this all sort of- was it the pharmacy? Where it had all the little different pills and things. I'd like to know more about those and maybe there was information there that I just didn't see.

Ashley Fisher
Yeah. Well, if there is and you didn't see it, that's also a problem. Right, with the stories and tales of the exhibition- of the exhibit, easy to understand.

Lisa
Yeah, I think it was clear it was a Victorian street. And you're sort of moving through to the backstreet. Yes.

Ashley Fisher
You also took a different trail than they normally suggest is that intentional was that to avoid things?

Lisa
It was to avoid that group.

Ashley Fisher
Do you think that detracted from the experience or the story?

Lisa
Um, yeah, because it meant that I couldn't see. I couldn't go to the school but there was that whole section. And where there's I think it was a toy shop back there – I think it was a toy shop – anyway, and I know there's a couple of shops behind that little school but certainly I didn't see any of that.

Ashley Fisher
Sure, yeah. And overall noise level in the Victorian street?

Lisa
Fairly loud.

Ashley Fisher
Quite echoey too.

Lisa
Yeah.

Ashley Fisher
And the light level in the Victorian streets.

Lisa
I mean, it's dim. But I like that. Yeah.

Ashley Fisher
But as someone who- but as a looker not a reader, yeah, it doesn't really make that much [difference]. Yeah.

Lisa
So if I wanted to read everything, obviously, it'd be a bit dark, so I'd get that for anyone with any visual impairment that would be quite dark. Yeah. That's why I say it for me.

Ashley Fisher
Yeah, exactly. Yeah,

Lisa
For me It's okay.

Ashley Fisher
And enough places to sit and/or rest?

Lisa
I think there just needs to be a little bit more to sit down

Ashley Fisher
Or at least a little bit. More. obvious.

Lisa
Yeah. Yeah. Especially if I was, you know, maybe just wanting to sit down and kind of soak in a little bit. Or if I wanted my son to go out and explore.

Ashley Fisher
Yeah, around a little bit.

Lisa
Yeah, yeah. There's nowhere for me to sit that I could really see. Yeah.

Ashley Fisher
Okay, so now let's talk about just what was your favourite thing about the museum?

Lisa
Just the Victorian street with all the different little bits and bobs? Yes. Because I like that kind of stuff anyway.

Ashley Fisher
What do you like about it?

Lisa
It intrigues me with all the little bits and bobs that people used to buy or that belonged to people. I quite like those kinds of things myself, little momentos. I just would have liked to

know where it was from, who it was from, so the history's there. Treasure boxes and things Yeah.

Ashley Fisher
What's your least favourite thing about that museum?

Lisa
I think I'd have to say the child died bit. it's important, but I... Yeah, I don't think it's appropriate, the location. Yeah.

Ashley Fisher
I had two miscarriages between my two kids. So like, seeing that is not an area I'd particularly like to see. Like, yeah. And also the height of where they put the picture kind of bothers me. Yes. Quite child height. Yeah. Yeah, it is important and I think that it should be somehow there but maybe we need to think about the presentation a little bit.

Lisa
And also it's the very first thing you see when you walk in the children's section Yeah, so I don't quite understand why, why would it be there. Yeah, I think generally we need a better relationship with death and we need to talk about death more. Yeah, but yeah,

Ashley Fisher
So what's one good thing related to disability and accessibility in relation to the museum?

Lisa
For my disability or disability in general?

Ashley Fisher
Anything. Yeah.

Lisa
I mean, I would say, I didn't use it, but I know there's a lift. I know there is disabled toilet. I know that is the ramp going in on the entrance. So I think some of the physical stuff to say is that it's a very old museum that's very limited. I think they do quite well for physical access. All right,

Ashley Fisher
and what is one bad thing related to accessibility or disability?

Lisa
Layout. For someone who has anxiety, it's just not very clear with where- I know they explain to go through the door and bump left but it's like a little maze to even just get to the Victorian street from there.

Ashley Fisher
I think that's particularly significant because you are so well acquainted that it still feels like a maze. Yeah, yeah. Did any barriers or easy fixes jump out at you that way over there- While we were there?

Lisa

I didn't actually see a sign to say where the stairs were to go upstairs. In the Victorian Street.
Yeah, that might be there, but I didn't see it.

Ashley Fisher

Well, if you don't see it.

Lisa

That's still the same.

Ashley Fisher

Okay, we didn't use any particular accessibility tools there. But do you think that there were
any that they could have supplied to you? Even if it's something as simple as, you know,
signs or maps or layouts or something like that.

Lisa

Maybe they could just hand out a map to people just to kind of say what the usual route
would be, how to get there, as in how to get to the Victorian Street. Yeah. Where the steps
are, where it brings you out.

Ashley Fisher

Feels like that's a museum that's really easy to get turned around him.

Lisa

Yeah. Yeah.

Ashley Fisher

What do you think the museum should design into their exhibitions from the very beginning?
Since the community room and the temporary exhibition space tend to change fairly
regularly, yeah.

Lisa

For me, it would be having more handout sheets to just pick up and read. Because I tend to
scan if I- if it's just on the wall or something I tend to just scan it. Yeah, whereas just a bit
more time I just hold it in my hand where I'm not sharing it with someone else. Yeah, I would
spend a little bit longer not kind of feel pushed to keep going. And also it's not very clear that
there are exhibitions upstairs and they do change.

Ashley Fisher

I didn't realise that the last room was the community gallery that changed, so even though
there are signs that say the dates it's gonna be there.

Lisa

yes and it's moved, so that that used to be in a different section, it's been moved to that area
okay so that there's a bigger space. yeah if you don't need just... like I say, I know the
museum so if you hadn't already been there before I mean...

527

Ashley Fisher
How did the staff make you feel?

Lisa
Welcome. Fine. Yeah. I mean, I get self conscious just because I know them and they're probably thinking what is she doing? Yeah. But yeah.

Ashley Fisher
Do you feel like you were treated differently than any other visitor?

Lisa
Only in that... because they know me? Yeah. But before I knew them, I always felt it was a friendlier place.

Ashley Fisher
okay.

Lisa
So, my husband used to work at a different museum. And I very rarely went into that one. I still don't know that many of the staff members he worked with whereas this one, I know a lot more.

Ashley Fisher
yeah, yeah. In my experience, each museum has a very different feel.

Lisa
different dynamics.

Ashley Fisher
Yeah, exactly. Yeah. At my museum,  We all are based around this one small desk, that's probably about the size just of the exterior of this. So four of us on any one shift, we have to get along, And you can tell that we all get along because we have to spend so much time together. Whereas, another Museum, there's two staff members, one in the first entrance area and one that travels around through the other ones. And like, they may say hello to each other. Yeah, you can just tell Yeah, yeah. Do you think you would have been treated differently if your disability was visible?

Lisa
Yeah, yeah. So I think if you come in... if you have a physical disability, I think people are much more comfortable with offering you help. Yeah. Or asking if you need any help, they would, you know, "just let me get that door for you" there would be something then that they would, you know, I think they would be much more open to asking you if you need help. Yeah. Which can be bad as well because it can presume that just because you're in a wheelchair you need help. Yeah. And you're not independent. So I suppose it goes both ways. But they wouldn't look at me, especially because they know me. They wouldn't look at me and say Do you need any help today? Sure. Yeah. And if they did, I'd probably say no. Even if I was really anxious. Yeah.

Ashley Fisher
In going around other museums, have you ever felt overly anxious or on the verge of a panic attack?

Lisa
Yeah, yeah.

Ashley Fisher
Have staff ever reached out or do you just get the British? Let's ignore it, it'll go away.

Lisa
No. So I think I just dealt with it myself and they probably wouldn't know that it was a panic attack. I've had them just outside the city museum and my husband was working at the time. So I rang him and said, I've just had a panic attack. I was at the German market. And the staff were good, like the, they let you have a room to sit down and my chair got a drink and stuff. But again, you know, they knew me. Yeah.

Ashley Fisher
So, yeah, yeah. Which kind of, yeah,

Lisa
So if I had gone to a museum in York, by myself, and I was feeling a bit anxious, yes. And I felt like I was on the verge of a panic attack, I would just leave the museum. Okay. I don't think it would ask for help Yeah. It's happened to restaurants before where I just said, Oh, I gotta get out, yeah. actually asked the staff for help.

Ashley Fisher
Would you accept him?

Lisa
Yeah.

Ashley Fisher
Sometimes asking for help is really difficult. Yeah,

Lisa
I think it depends on if I did feel like, Okay, if I just get outside, then I'll feel Okay, then I wouldn't accept help, you know? Yeah, but sometimes it is a case of, you know, can you just help me sit down? Get me a drink? Yeah.

Ashley Fisher
This might be a bit of a throwaway question, but would you visit Abbey House Museum again?

Lisa
Oh I so would!

Ashley Fisher
Okay, so if you could tell the museum one thing regarding the accessibility of their site what would it be?

Lisa
Um just not presume that because I haven't got you know, a leg missing that I'm okay. That I know my way around. And just probably think about the signage a little more. Because obviously they are comfortable and they know the layout and it is probably easy for them to not realise how difficult it can be to get from the shop to the Victorian Street.

Ashley Fisher
That's perfectly fine. I forgot to ask this but how long do you normally spend in a museum?

Lisa
Probably about an hour, maybe two hours. It depends on how big it is, What which parts interesting

Ashley Fisher
perhaps to do with how busy it is on a day? Oh yeah.

Lisa
So I wouldn't go to have lunch. It'd be like, right we'll go from you know, like this morning, half 10 till half 11-ish and that'd be me done. yeah

Ashley Fisher
Wonderful. I do have one curious question. If they were to do things like autism hours or quiet hours where they limit the number of people that are in there, would you be more likely to go?

Lisa
No, I wouldn't. I'd encourage them to do it for other people, right. But...

Ashley Fisher
you wouldn't feel that that was necessarily something that

Lisa
Yeah, I wouldn't feel it was for me, okay. And feel. I feel like if there's something that is for autism then those people with their carers or their families. should be able to enjoy that and not feel like they have to share that space and be apologetic for outbursts like that so that's just me being in that they deserve that. That's that time and space. Yeah. Yeah.

Ashley Fisher
Interesting.

## 9.4. Follow-up Interview.

Due to distance, Lisa and I did not meet in person for this interview. Instead, we spoke over the phone whilst I recorded it on my end. This phone call occurred on 27 November, 2019.

**Ashley Fisher**
All right, so I just wanted to start out our chat with just sort of a recap of things we talked about last time. So one thing that you wanted to tell the museum was that they shouldn't assume everybody's fine just because they don't have any visible disability. Is that still accurate?

**Lisa**
Yeah.

**Ashley Fisher**
Okay. And also to consider their signage because they probably need some fresh eyes.

**Lisa**
Yeah.

**Ashley Fisher**
Okay. And you would definitely return and your favorite aspect was probably the Victorian streets.

**Lisa**
Yeah, yeah.

**Ashley Fisher**
All right, excellent. How did you feel the next day?

**Lisa**
Um, it was a bit weird, because I felt really tired. I actually had a panic attack that night, which I haven't in a while. Yeah. So, yeah, I was quite tired the next day. I'm feeling a little bit anxious. But I spoke quite a lot with my husband, obviously. Yeah, we talked about things that the museum has been doing and the feedback that they've been getting anyway. And it's, it felt good to actually say, you know, not criticize, but just to say, actually, this is how I feel when I go to these places? Yes, kind of acknowledge that that happens and yeah, yeah, that's very good.

**Ashley Fisher**
Okay, oh, I might have to follow up and see what that feedback is. Alright, um, how significantly did your disability affect the visit, do you think?

**Lisa**
It affects in the sense that we missed out because wherever it was busy, the pub and stuff I didn't go in and I know that it could have been somewhere that I don't know, then it probably would have been worse because that would have been having to plan, you know, the train journey, right?

**Ashley Fisher**
When you were avoiding those crowded areas, was it more because of the noise because of the space? Because it was, you know, sort of cramped? What do you think?

Lisa
Yeah, I think it's more space with me. Okay.

Ashley Fisher
Some of those places can get very small in that museum. Did this museum remind you of any other museums that you visited in good ways or in bad ways?

Lisa
Um this one street scene and that always sticks out in my mind because it's similar to the school. Yeah, and I like that.

Ashley Fisher
Yeah, that's York Castle Museum.

Lisa
Yeah.

Ashley Fisher
Any others it brings to mind?

Lisa
Oh, maybe JORVIK? Yeah. And that's because I think that's the kind of museum I like, where you are so surrounded by the museum type thing. Yeah, it's not just an object or reading it, I like the whole kind of scene.

Ashley Fisher
Yeah, yeah, there's a museum from where I'm from called Cantigny Park, and it tells the history of an army platoon or something that's from that area? And one of the things that it does really really well is it takes you through the wars that they were involved in. And it's set up like the Victorian street at Abbey House, like you walk through a recreation of a Paris Street and some trenches from World War One and like, you go on to the beach when they were on Normandy, it's really really cool. I mean, it's this tiny little museum, but it's honestly one of the most effective things that I've ever visited. Just because you feel like you're there.

Lisa
Yeah, that's the thing I like. I guess JORVIK is the same that sticks out in my mind again, just when you get in. I don't know if it's still like that. But when you get in the car and you go around, and it stinks.

Ashley Fisher
Yes. We've even updated it so there's multiple smells now. So it's not just poo the entire time. There's a nice part where it smells like burning wood so it's almost manageable All right, and do you think there are different expectations put on paying versus non paid museums from a customer's point of view?

Lisa

Um yeah, I think you expect to get a little bit more and more money so if I was comparing Leeds City Museum, that's free, to Abbey House, you probably get a lot more experience if the museum's not free. Yeah. That can kind of detract from it a little bit. Because you notice the expense as you go into the museum, you're expecting maybe a bit more experience.

Ashley Fisher
Okay. Um, if we had taken this trip on a bad day for your anxiety, do you think it would have changed the experience? Or even going?

Lisa
I think just because I know the museum I would still have, I would still have gone but I probably would have been there even less time. I think I maybe would have broken it up with going for a drink and then go back in, something like that. Okay. Yeah.

Ashley Fisher
All right. And this is, this is my last question, but it's a quite a personal one. Do you consider yourself disabled. Okay. Do you consider yourself a person with a disability?

Lisa
No, no. Okay.

# Appendix D – Field Notes.

This appendix contains all the field notes I created when conducting interviews and site visits with participants. They are arranged alphabetically by participant's name – except Teagan and Kasi, who are listed together.

## 1. Aaron.

### 1.1. Pre-visit interview.

- OCD
    - Anxiety – don't enjoy it
    - Physical manifestation
    - Excessive cleaning
    - Started around 4
    - Quarrantine
    - Doing things in 4s
    - Chronic
    - Joey Ramone
    - Intrusive thoughts
        - Worst outcome
        - Give up mostly
    - Magnetism to a thought
        - Need to say fuck it – leads to recklessness
- Bipolar Personality Disorder
    - Rapid cycling
    - No routine or prediction
    - Both cause depression
        - Not a brain chemistry thing
- PTSD
- Asperger's – high functioning
- Coma of mum at 9 – PTSD from tht
    - Makes jokes to deal
    - Definitely on autism spectrum thought not massive
- Social anxiety from OCD
    - Notice the mental
- Reads lots of poetry
- Not great for archaeology papers
    - Writes it as a poem, the edits – it's a whole process
- Degree in classics already
- Biochemistry study in 1962 – lack of ??
    - Alcohol can ease the OCD
- Does cold showers, exercise, meditation, mantras to help
- Don't know any different
- Asperger's
    - On medical record
    - Maybe misdiagnosed
    - But he "seems" fine
    - Especially when on an upcycle
- Natural History Museums – empty on bank holidays
- Enjoy Halloween
- Specific museum – Smithsonian

- - Look into the history of a place
  - Passion is stronger than anxiety
- Fine if with someone
  - Doesn't like to visit a place alone
  - Chronological (??) – but avoids big crowds
  - Interest must overpower everything else
- General feel/idea of the place
  - No access page – no expectation for his disabilities
- Gandalf's advice
  - Smoke a pipe
  - 1 hour to pack perfectly
  - Needs to use a match
  - Needs to be very aware
  - Take a pipe to remind him to be in the moment
- Zippo lighter – plays with as comfort
- No preparation
  - Doom is always impending
  - Quite fatalistic
- Hear glass smashing
  - Adjusts
  - Read Marcus Aurelius
  - Sporadic reading
  - Cold shower
  - Meditate
  - Cigarette
  - Call mum
  - Get ready
  - About 3-4 hours to prepare (mentally prepare)

## 1.2. Site visit.

- Skipped fireplace room
- Quite quiet going around the place
- Has a pipe as a comfort object
- Went up to the big Charles I painting and looked at the altar piece
- Using the hand held panels
- Green set
- Has questions – but didn't want to ask the room guide
- Going back and forth between the different types of panels – using the laminated booklet too
- Interested in the history of the building itself
- Went up the great hall staircase first
- Looked at the clock and waited for the panel to be open
- Yeah not a great placing I had to wait on the stairs to get up to the landing while people were reading the board
- Doesn't like Yorkshire terriers
- Very rambly
- VERY rambly
- Switched a light off in the Kings room
- Wants to touch things it seems
- Mention of Queen Alexandra and her deafness
- Talking about the light levels as well
- Finally asked a question – asked why there isn't a statue of Thomas Cromwell in York
- Poor room guide has literally no idea – they know a lot more about Frank Green

- And now he's just chatting – but the room guide is trying to be nice and accommodating
- Oh bless his heart
- Passed him off to a friend who knows much more about medieval stuff
- And they are juuuuust talking away
- Alas he still has no answer
- Looking at lot at the objects
- Doesn't like the modern wing
- But this does point out the lack of flow in the building – we've skipped the first half of the building
- "Sounds like Frank Green had OCD"
- Not a Frank Green fan then
- But my pens spilled again and I've got red ink all over my hands
- He does totally love velvet
- He's looking at the children's dress up
- Bit unsteady on his legs – might just be his lankiness
- Seems intrigued by the writing on the walls
- Also the demolition and restoration panels
- Seems to like the thread of Frank greens life in general, just as a way to feel connected to the house?
- Yep bit unsteady on his legs rn
- Retracing our steps now
- Looking at the art
- Okay we are checking out the other part of the house now
- Blue drawing room – looking at odd objects
- Record player
- Looking around to see where a sign is actually associated with
- Dogs of Fo
- Very interested in them tho
- Reeeeeally examining them
- Too dark?
- Moved inside of the furniture
- He's not touching anything but crossed into the "out of bounds" area
- No comment from room guide however but he's talking to a couple
- Who looked vaguely horrified that he walked into there
- Examining the ship
- From all sides
- Very quiet in here, not super chatty
- "what's the context"
- Room guides are slightly awkward with him – has to do with his questions? Oddly wording some of them
- Man lots of people are interested in the Eagle statute thing
- Pausing on the staircase to look at the paintings
- Started to reach for the banister but stopped – decorations?
- Oh he is ITCHING to talk to the room guide in the queen's room about Frank Green
- The room guide is talking about the dichotomy of working for Frank Green
- "how did he die?"
- Avoiding gaze of the male room guide
- Is he a megalomaniac
- Might have been gay
- Ah a few moments in, he took his glasses off and is looking at the guide
- When he found out Frank was a commoner
- Gone on politics a bit
- But mostly how we don't know anything about his politics
- Fair but firm employer

- Asked about how he treated his servants
- Interested in the Royal connection as well
- Very comfortable around the male room guide – following him around
- Asking about Frank's sexuality
- More of a vague thing than any actual evidence e
- Spending a LOT of time in the queen's room
- Chatting with him about Gloucester now
- Has only said thank you to one room guide so far, and it was immediately after I had said it to the previous one
- Gets SUPER close to the things but doesn't quite touch
- Looking at the clock again
- He likes tapestry
- It's very phisophical
- Philosophical
- Got out the magnifying glass for the needlepoint
- He's examining it very closely
- Some people were struggling to get up the stairs
- Really examining the stairs
- Prefers the older tour guides
- It's like his gramp telling him things
- Surprisingly busy in the shop
- Didn't end up getting anything from the shop, which is fine, he at least had a good look around

## 1.3. Post-visit interview.

1. No 3G – American SIM
    1. Would have been lost
2. Yeah
3. Bit, but a bit all over the place
    1. No "order"
    2. Layout – sporadic
4. n/a
5. I guess – burying; no
6. Yeah – capitalism
7. Yeah
8. Weren't dirty – hand dryer doesn't work for him – different spacing
9. n/a
10. n/a
11. Good at speaking, warm, welcome
    1. Didn't know much outside the Treasurer's House stuff
    2. Happy to work there
    3. Queen's Room guide was especially great
        1. Humour
        2. At least knew she didn't know

Yeah, different from NH museum
.       Different demographic
Handheld display
.       Gotten better at touching things
a.      Hygiene used to be a concern
n/a
n/a
n/a
n/a
Pretty good – guides were loud enough to listen without being an active participant

537

.       Recordings
a.      Prefer to listen to a recorded thing
b.      "How many times has he said the same thing"
c.      No pressure – natural voice
n/a
n/a
Not consistent
.       Prefer dark rooms
a.      Smithsonian – spotlight the text to read
- Toilet was too bright
- BDR – fine, didn't notice
- More interested in Frank Green
- No – everything said don't
32. Tapestries – Frank Green
33. Wasn't busy – nice and open
- Need more of the history – if you don't want to talk to someone – more info about the paintings
39. Staff were good – seemed to pick up if you wanted to speak or not
41. Look in their eyes, taking steps back, negative reactions expected
42. With a friend – didn't super enjoy it
43. Days with no or low staff, less pressure to interact and with more text – less social intereaction

## 1.4. Follow-up interview.

I was unable to conduct a follow-up interview with Aaron.

# 2. Alfie.

## 2.1. Pre-visit interview.

- Dyslexia – takes a lot longer to read
- Can only see out of one eye
  - o No depth perception
  - o Only out of one eye since forever
- Monocular vision
- Not much difference in print vs digital
  - o Takes longer to read on paper
- Facilities – café
  - o Exhibits
  - o Cost, hours
- Google/their website
- No screen reader or text reader
  - o Zoom in to make text bigger
- Bring someone – take a photo of info to read later
- Motivation to visit
- Ask questions of the person – summarise a board
- "Unofficial companion"
- No emergencies

## 2.2. Site visit.

- Mentioned we can sit anywhere

- The letters on the subtitles are slightly blurry – refocus?
- Quite a bit of text on the panel
- Hard to focus on the video because of noise from other areas
- Really likes to touch things
- Being able to pick up is helpful
- But the font is kinda terrible
- Words all blend together
- Not quite bothered enough to focus
- The light isn't helping with readability
- Very small text on here
- Slightly difficult to tell where to stand
- Uneven flooring in the great hall
- Easier to read but still can't read it
- Old phone – audio tour?
- Put claro scan pen on it
- Put audio stuff on it
- Smaller text – difficult to read
- VERY small
- Yay smelly things!!
- Can read these pretty alright weirdly
- Can read lapis pretty well but amethyst is almost impossible
- Nice image
- Top is easier to read than the bottom
- Background image??
- Being able to pick things up is good – can bring it close enough to read
- This one isn't too bad to read
- Everyone loves the wand activity
- Lots of overlapping noises
- The sounds from lesser chamber and greater chamber are bleeding into the parlour
- Sign attached to the stand is hefty – the sun was shining very brightly on it
- Bigger text is easier to read – line spacing is an issue?
- More space between the lines would be helpful
- Makes it easier to move to the correct line
- Very hard to read anything in the lesser chamber
- Takes a lot of energy to read it
- Audio things are more useful
- Uses audio guides when he can
- Can't read these basically at all
- Text size, line spacing, lighting all make it difficult to read
- "Nice shadow display" other visitors
- Text too small
- Look at the difference in lighting!!
- Body text too small
- Light out
- So much text
- Add an audio element as a way of sharing info in a different way
- SO much less energy to listen than to read
- Paint the thresholds – more consistent signal
- Cannot read the text over the pattern
- Less contrast in a dark room
- Odd reflections in the acrylics
- Means you have to move around to see the whole sign
- Buttery – the individual details aren't so important so the lighting isn't such an issue
- Can't see the cool things under the table because it's so dark
- The candle is actually helping here

- Actually not that bad to read – about the same as the smaller text
- Text is too small
- Lighting in the cabinets is okay
- Text box and bigger font
- The steps are a bit slanty
- Glare on the board
- Small labels in the gift shop

## 2.3. Post-visit interview.

- No signs until coffee yard
- Quite – building work didn't help
- Couldn't tell where the entrance was

Audit

1. Once the signs were there – the building itself was fine
2. Not really
3. Odd layout – knew where to walk to, would have missed the study/office area and beyond
4. Pretty small – just look at the item itself
5. Yes
6. Yes – would have been difficult for less mobile
7. Yes
8. Yes
9. Yes – little drain thing was a trip hazard
10. Yes – good answer, led to nice discussion
11. Yeah
12. Interactive was good – better understanding, likes touch aspect
13. Not everywhere – just everything could be difficult
14. Some places were fine – picture overlays were bad, poor lighting was bad, just lots of things made it difficult
15. 1st video (steward's room) hard to hear, dream room was fine
16. Understood the part about the witches – not many narratives beyond that
17. Fine – good noise cancelling (from outside)
18. No
19. No
20. Not bad overall (in parts)
21. Hard to read in the study/office – moved to block the light glare
22. Yes – food areas (pantry/butlery), lesser chamber – lots of variance
23. Imagine yes – didn't really look (will sit anywhere)
24. Better – bigger, better lighting, font size, materials, boards (moveable boards helps)
25. Better than the rest – not bad
26. Yes – the one he did get
27. Not bad
28. Good
29. Didn't notice

General questions

1. Interactive – not many museums are
2. Boards – frustrating very draining
3. -
    1. Sound was relatively okay (volume, noise quality); good for colour blindness; interactive – more senses involved, other senses to rely on
    2. Boards were hard to read; mobility limitations; steps are slanty (inform people somehow? Like with the threshold signs)
4. Steps, thresholds, many stairs in general
5. -

540

1. Audio component (able to listen to info rather than read)
2. Boards could be designed better – consistency, matte material, even in low light, things would be better
6. -
1. Friendly, welcomed, just a thing
2. No – just a thing – no hassle, friendly enough
7. Probably – interesting place
8. Make it accessible
1. Boards need sorting out
2. Thresholds and steps disappear
- Phone app?

## 2.4. Follow-up interview.

- Pick up boards were better
- Always fun – costumed interpreters are just interesting in general
- Phone app – less text, more audio, more info on the building
  o Building was the most interesting thing
1. Yes
2. Ashwell Museum – more about the building, more a part of the atmosphere
1. Hartfordshire
2. Community museum – all volunteers, really friendly there
3. Displays are quite good – being revamped
3. Natural History Museum – big, good info, fiarly interactive, relavent info
4. Yes
1. Paying – better standard, better access, more simplistic, more about bringing people in, less about the enjoyment once inside
1. Spacious exhibits, better furnishings, evidence of investment
b. Non-paying – sharing the info
1. Friendlier – there because they WANT to be
c. That being said, Barley Hall was quite friendly
Tired – less likely to read
. Wouldn't have bothered reading – mental energy
In some ways yes, in some ways no
. Don't really notice it
a. Fairly steady
b. But also it limits capabilities
1. Stopped playing cricket because no depth perception
c. Person with a disability
- Barbican – London – tech and how it's been built up – less about the artefacts and more about the process of making the artefacts

# 3. Amanda.

## 3.1. Pre-visit interview.

- Psoriatic arthritis
- Parents had psoriasis
- Attacks cartilage, tendons – not damage, but inflammation and fatigue, pain
- Genetic
- Under control, it's not too bad
- Injections 2x a week to dampen immune system
- Also heart failure – transplant ist

541

- o Breathlessness and fatigue
- Now fully retired
- Already reduced to half time – but it was still too much
- Retirement on health grounds – preserves pension
- Extra sleep – still needs an alarm
- Very severe fatigue
- Right hip and back
- Spondalosis of the spine
- Very stiff in the morning
- Cold is bad
- Temperature is a concern
- Places to sit – don't want a walker yet (pride)
- Stiff joints – heavy doors are a bane
- Wrists and fingers
- Steps and stairs are tough
- Blue badge in car
- PiP – mobility component
- Space things out – never 2 things in a row
- Belly dancing – good for her back
- Even an afternoon of rest wasn't always enough
- Planned our visit into the schedule
- Flares are so hard to predict
- Chronic fatigue is just awful
- Iron infusions
- Been to Barley Hall before for Christmas music with friends
- Recently to Burton Agnes Hall
- Read in a magazine or newspaper or tv
- Use of advertising is key – go to see something
- Annoyed by the art gallery
- May review how she pays for things
- Used to quibble over paying
- Residents weekend – likes to plan things, but often feeling lousy and then doesn't follow through
- Special cushion for sitting – hard surfaces are bad
- Forget things she needs – planning things
- Might use internet more – learning how to use it better
- No planning for eventualities
- Forgets water
- Pain pills in bag
- Not long to get read
- Just grabs bag and keys
- Forgets keys and phone a lot

## 3.2. Site visit.

- Planned where to park
- Staying in one position too long can be challenging
- Kipling Hall – hadn't changed it, dusty and shabby, not changed, put in a barn for lunch with carriages and carts and just played on them
- 50 years later and she still remembers it
- Sensory experience
- Amazing how long that buildings lasted back then
- Basic information
- Okay for info but wanted a bit more info
- Liked the history of the excavation sign

542

- Wants to know where some of the mentioned artefacts are now (specifically steelyard weight)
- White on black is difficult to read
- Concentrate with this colour contrast
- Size is fine – might be the font that's making it difficult to read
- Bit blurry
- Wants dates
- Rather than eras
- Map would have been helpful to conceptualise the layout
- Doesn't want grab handles on doorways but the steep stairs are difficult to get up and some kind of hold would be helpful to help step up
- SEN school in at the same time as us – they were upstairs most of the time
- Bit noisy but not too disruptive
- Nice light door on toilet, screw taps were a bit stiff
- Needed a pause halfway up the stairs
- Interested in the layout of the medieval building
- And how each of the rooms would have been used during that period
- Subdued, dim light in the greater chamber
- Could be a bit brighter
- Liked thst sign, keeping with the theme
- Temperature will dictate what she Carries
- Handheld signs at other exhibitions (London especially)
- Easier to read the handheld signs rather than the wall signs
- Kept her coat on through the visit, suggests bit chilly
- Feels a bit freer when she doesn't have to carry around her coat and bags
- Wants to know info of the use of each room during the Snawsells people
- Period
- Too dark in the lesser chamber
- Want to pick it up to read but not sure if allowed
- Immediately picked up whatever she could
- Take home the postcard to read at home – too difficult in this light
- Likes being able to pick things up to read
- 4 others in the gallery when we were visiting
- WOW even my hands are getting chilly
- Exhibition Harry Potter in London at BL was wonderful
- The hexfoil object wasn't very clear
- Was intrigued by the children's stamping activity
- Liked reading all the panels
- Gallery was well lit
- Wand making craft was "sweet"
- Picked up the wand board no hesitation
- Had a bit of a rest in the gallery
- Recognised mother shipton
- Liked the fireplace
- Wanted to know a lot of the history of the building like whoa
- Likes Romans
- Touched the stones – seemed to engage with sensory stuff well
- Another 3 more people
- Hand on the wall to go into the parlour
- Picked up horn book
- Liked feeling the surface of it
- Could sit on the bench without her cushion
- Interested in the roofing
- Very rainy today
- Chilly

- In the parlour
- Nice chat about textiles through time
- Always have to think about the seating
- REALLY liked touching the real furniture (chest in parlour)
- VERY dark in the buttery and pantry
- Didn't go into the pantry probs because of the step
- Loved the building puzzld
- Horn spoons are still used for eating eggs
- Tbh the school was less obnoxious than the two 20somethings that were visiting
- Limped a bit after going up the back stairs
- Kinda braced hersrlf to go down the stairs
- Migrated towards the shelf stuff in the gift shop
- Especially liked the gardening things
- Lovely interaction with Sarah on the desk – checking stock of tea towel
- Paul was quite helpful too
- Ended up going with the smaller price
- Went to Japanese tea shop on Blake Street

## 3.3. Post-visit interview.

- Fine to finds – looked on google maps
- Easy to find the entrance
- Flow was alright – signs help, small site
- Gift shops are always strange – how it is linked, didn't really read the signs
- Enough space, easy to navigate, easy to find toilet
- CLean – bit of a wet day, so clean enough
- No difference in attitude
- Might have been more helpful with a visible disability
- Welcomed – not too many staff on view
- Not always – hard to read white – not always well lit
- Not the best font
- Not light on dark
- Good level of noise
- Didn't get the story of the HOUSE – bit of day to day life but not a full picture
- Noise levels were fine – quite like the quiet
- Some places were too dark especially when stepping into a room, light is needed
- Lots of benches
- Lots of stuff on display – more about the feel of the place, left to work it out yourself – maybe the guide book would have helped?
- Lighting was nice and bright in the Great Hall
- Easy to get from BB parking
- Not easy to read
- Toilets on ground floor – easy to open door
- Some kind of grab rail would be appreciated
- Tiled floor is a bit uneven – easier to stumble
- Walking frame/cane ma help
- Raising lights in general
- Info as you enter – handheld signs, info on the room As you enter the room
- Cushion on hard benches was a nice touch
- Friendly – bit embarrassing about the whole price issue
  - Sort out the issue later, slightly embarrassing
  - Fed up by that point
- York is a medieval city – I accept that but things like a step into the building make it obvious

- o Don't need to over compensate – the ramp for example took away from the experience – let's find a way to make it fit with the rest of the building
- o Good for a family on a wet afternoon
- o Not a lot to grab your attention
- o Nothing that made it really stand out
- o Great for children and families
- o They need a Middleham Jewel – a star object that draws people in
- o Nothing extra really
- o There' a lot of medieval history in York – needs something special
- o Wouldn't visit again
  - ▪ Would go to a special event
  - ▪ Would take someone if they were visiting and were particularly interested

## 3.4. Follow-up interview.

- Went to the garden centre over the weekend, going out for lunch that day
- Next day (it was cold and damp)
  - o Relaxed for the afternoon
  - o Might have been poorly but not linked
  - o Nice and relaxed
- Knotted rope hanging in doorways?? Instead of grab rails
- Likes to visit special exhibitions – read everything
  - o Once in a lifetime experience
- More of a looker in places like Barley Hall
  - o Reads things that are interesting
  - o Revisits favourite objects
  - o Not always clear how the labels associate
  - o Crete – Hanya – Roman museum – post card info
- Temperature – would have cancelled on bad days – might have skipped
  - o Have to cancel sometimes
  - o Nice family who is very will to help – going with someone elsse is helpful
- Temperature had more of an impact – not a lot of natural light
  - o Info sheet that's portable
- Go with a friend who was keen
  - o Liked special events
- So much stuff in York, you reall need to stand out
- More like a resource for schools, good for tourists
  - o Easy to understand way of presenting information
  - o Burton Agnes – adds a certain extra element as the family is still there, deeper connection knowing that it's still an active house
  - o Liked the restoration, but not the same continuity
    - ▪ Give a bit more of an experience of the actual room – less exhibition
- Richmond Castle (Mary Queen of Scots was held here) – connection to actual people through objects
- Non-paying vs paying is an interesting topic
  - o Non-paying are a wider audience
  - o Paying are smaller, need more of a push to grab people in
    - ▪ Scottish Art Gallery
    - ▪ Families don't have to worry about paying
  - o Rail Museum as a pseudo day care
    - ▪ Only non-paying place
- Edinburgh Festival
  - o Exhausting after one day
  - o Art gallery outside of town

545

- o Lots of effort to get there
- Buggies
  - o Hire them at the site
  - o Railway stations could offer them

# 4. Amy.

## 4.1. Pre-visit interview.

- Hypermobility syndrome
  - o Involves pain, stiffness in joints
  - o Hip dislocates, which can impede mobility
  - o Knee pain – just walks a bit slower
  - o Almost fused joints (sorta the opposite of hypermobility, which was a younger thing)
  - o Shorter steps
  - o Hard to write – can write about half a postcard and then it gets painful
  - o Plans ahead – if having a long lecture the next day, doesn't write late at night
  - o A doer – difficult to hold back and therefore manage the condition
    - ▪ Pushes through the pain and discomfort on holidays because it's such a unique experience
  - o Sitting on a bus is hard – need to move
    - ▪ Can't sit with knees against the back of the seat as it puts pressure on that joint
  - o Recently diagnosed with scoliosis – which also involves sciatica
  - o Can't sit in one spot for very long
  - o Injured coccyx
  - o Basically a physical (hidden) mess
  - o The HMS may be related to something deeper, but no diagnosis
    - ▪ However, she's very convinced of it
- Mental Health
  - o Mental exhaustion is a big thing
  - o Anxiety loves to make her overthink – it's so tiring
  - o So much overthinking – logically know it's not the end of the world, but anxiety doesn't listen to logic
  - o It does, however, involve lots of planning to make sure things are prepared for
  - o Obsession-oriented
    - ▪ Food especially – 'safe' foods
    - ▪ Brain refuses to accept certain foods are food, like unprocessed meat or vegetables (only processed ones are safe!)
    - ▪ Worry about other people's safety
      - ▪ If they don't answer right away, immediately assumes they're dead
      - ▪ At least it's not depression conclusions
  - o Intrusive thoughts are big – not extreme as in 'I could push someone in front of a train' but more realistic ones like 'I could lick their hand' or 'I could shout out in the middle of a test'
    - ▪ Somehow more terrifying because they're more realistic
  - o Fatigue is big – especially from joint pain
    - ▪ Needs a solid 9-10 hours of sleep, and even then that's not always enough
  - o Mental exhaustion vs physical exhaustion
    - ▪ Can often power through it but it's not good

- Sometimes have the physical energy but not the mental; vice verse as well
    - Life is much harder this year than last year but nothing more has been added on
- Getting ready
    - Lots of balance is required – can't carrying too much (back problems) but need enough to feel secure
        - OCD is overpacking?
    - Items
        - Diet coke (jolt of caffeine and sugar)
        - Water
        - Book – calming tactic, safety net
        - Pain killers
    - Check weather – cold has a big impact
    - Prepare the night before – hard time waking up, so chronically late to things
    - Check how outdoors the place is (for temp)
    - See if there's a café – blood sugar can drop very fast (if no café, then bring a small snack)
    - Uses the museum website to check normal things
        - Hours
        - Location
        - Mostly looking at photos
        - SOMETIMES checks Trip Advisor but mostly for photos
        - Normally hard to find the prices?? Especially if there's a student price
    - Tries to minimise walking
        - Plans a route – could 2 buses work? Could just take an Uber?
    - Hates using trackpads – DSA gave her a mouse and WOW a whole new world
    - Uses sticky stretchy athletic tape
    - Been advised NOT to use a stick – moves pain to her wrists rather than getting rid of it
        - But it'd also worsen the scoliosis as it would lean her to one side
        - Would need to use two crutches – but then wouldn't have hands free and therefore couldn't really do anything else
            - Not ready for that at this point
            - Not a pride point
            - Would prefer to use something like that as people would *notice* she has a disability
            - Example: visited Tower of London and there was a 2 hour queue, but she wouldn't be able to stand that long. Talked to a Beefeater, explained her disability and that she simply can't stand that long, and they let her do a queue jump (very understanding staff, but felt judged by other people – anxiety brain?)
            - Same with using an accessible toilet – has to do with leg space – worried that people will be judging her for using it without a visible disability
    - All the preplanning really is for possible eventualities
        - Low blood sugar
        - Pain flare
        - Tiredness
        - Lets friends know if she's having a rough day (ie, cranky because depression, needs to go a little slow today, etc.)
    - Goes to museums alone a lot
    - Checks for certain eventualities

547

- Rain
- Eczema – types of clothing
- Snacks
- Water
- Takes about 5-20 minutes of research, depending on museum
- Night before takes 5-60 minutes
  - Constantly checking bag
  - Worrying about temperature control
  - Anxiety brain
  - Lays out clothing (sometimes several options) night before

## 4.2. Site visit.

- There is in fact a green sign, though not quite the kind that Ellie was talking about
- Much quieter than it was on Friday
- Amy likes to stand on a person's left hand side
- More overcast day
- Quite low lighting
- Not a whole lot of natural light
- Wandering between people no problem
- Unsure if she could pick up the chairs have eyes sign
- People are taking boards and basically standing there
- Ellie skipped the dining room
- Went STRAIGHT for another sign
- FINALLY UNDERSTOOD SHE COULD SIT ON A CHAIR
- Like having multiple copies of the same hand held board
- LOVED the tree
- Only one in the blue drawing room and the guide was a bit too awkward to talk
- LOVE the little touch of the champagne glasses
- Quite outgoing and had no problem going up to the room guide
- Talking about the style of furniture – country of style and time era
- Talked about the lighting again – ambiance, conservation, etc.
- VERY personable
- Went and sat while talking to the room guide, had no problem doing it
- Quite upfront about her disability
- Taking down the name of Frank Green
- And we're talking about the ghosts
- The popular roman soldiers first of all
- Cyril is the room guide
- She had heard the story as a young child and knew the basics of it
- Talked especially about the clothing of soldiers and the "proof"
- Talked about another one in the upstairs
- A ghost who sits in the chair
- Who appears to children
- Admits people like to hear about the ghost stories
- In the tapestry room
- Cyril clearly likes these stories – treading a line between believing and not believing
- And another ghost story from another NT property
- In Wales
- From his sister
- Five or six family groups have gone through the room while we've been here
- Absolutely lovely chat
- Comment on the banister garland again
- Far less room guides today too
- Asking about ghost stories from the tapestry room

- New ghost story! Someone was murdered in this room
- Kinda wandered off in the middle of the conversation
- Asking questions of basically every room guide
- Not SUPER chatty guide but still nice
- Stopped at the top of the strairs
- Confusion over layout
- Prefers asking questions to the guides than reading the answers
- Wants instructions! Too much freedom
- VERY confusing to get in and out of the toilets, but also a very heavy door
- Same problem with the sign on the register

## 4.3. Post-visit interview.

- Eh on signposts – used google maps, not the easiest place to find, more signs would be helpful
- Roughly knew the location
- One way walking systems feel more secure – not super easy to find a path there; would like a more guided path
- William and Mary staircase was nice to get up – shallow steps, wide passage
- Great Hall staircase was quite narrow – couldn't pass people but at least one way direction
- Gift shop stairs VERY narrow – for both up and down, good bannisters though
- Spacious rooms, not too much in the way
  - Family portrait room was a bit smaller but no danger of bottleneck
- Has a hard time NOT going her own speed as it can be painful to be sped up or slowed down
1. Not really
2. Didn't immediately notice
3. Okay but maybe a bit more structure? Not a map, but a trail disguising a map would be good; needs to be 'markable' so she can check off rooms
4. Put a sheet over the till because it doesn't look 'closed'
5. Not big, but fine for when we went
6. Yeah
7. No
8. Yes
9. Probably was
10. Bit awkward, didn't cross his mind to be more audible
11. Answered questions nicely, didn't really ask for help but certainly asked questions
12. Yeah
13. Yes – not much written – liked the oddities trail – not obvious locations, so perhaps missed some, liked the multiple copies
14. Yes
15. Quite dark so didn't help – maybe bigger font to mitigate the darkness – good that it's not text based
16. Loud enough – mix on the Roman video was bad, sounded like audio feedback
17. Family portrait room was a bit difficult to follow
18. Yeah – doesn't like it too quiet where the only sound are own footsteps – ticking clocks were annoying
19. Perhaps the café?
20. Blue drawing room – but it didn't feel too bad, it was very atmospheric – not too solemn
21. Liked it – like it a bit darker
    1. Has an eye muscle strain thing – muscle ache (it's normal eye strain, but more susceptible to it)
    2. Too bright or too dark lighting can be a trigger

549

22. No
23. Frst room – fireplace room; also blue drawing room – made it calmer, plus nothing to read
24. Yes but hard to find – lack of places to lean or even rest a bag – "please touch" signs would be really nice, unsure on whether could touch tables or not
25. Whoops
26. I
27. Skipped
28. These
29. Questions
30. Will
31. Ask later
32. + room guides, – decorations on the banister
33. + hand held cards, – toilet adventure (REALLY heavy door, no phone signal in the bathroom but also no red cord which could be an issue if you need to call for help), no toilet check signs
34. How long it took to get to the toilet – also no signs through the rest of the house
35. Wore gloves all the way around – liked to pick up the signs and the small side banister on W&M staircase
36. Changing a few little things:
    1. Bannisters – making sure they're clear
    2. Not crowding the top or bottom of stairs
        1. Jester's window – felt crowded with so many signs so people wanted to stop and linger there, made it back up

Wanted to know more about the gnome trail – stand with leaflets or something
No
Welcome – sometimes guides can be enthusiastic but ignore any feedback, these room guides were more conversational than lecturing
Liked to have been treated differently – sitting especially, notice little things
Yes – could have been more involved
Yeah
Banister decorations, bathroom door

## 4.4. Follow-up interview.

25. Yeah
26-27. No text – good with guide, didn't see boards – sent photo
28. Mentioned the lower lights – with the guide; bit of history about the ceiling, not prompter
29. Bit quiet but chatting with the guide was fine
30. Like the darkness
       Chilled atmosphere – glasses can reflect the light, so she could have sat and enjoyed the atmosphere easily
31. Not obvious – sat on a window bench – obvious where you COUDLN'T sit, not as obvious where you could
   - Had a weird dream that night
   - Not a massive impact from HMS – out of breath, obvious oversight
   - Really liked the eyes in the chairs
       o Like the hand held aspect – don't need to ask for it
       o Not an extra step
       o Extra copies are great
       o Wouldn't go ask/request any materials
   - Leg pain and fatigue the next day
       o Brain fog
       o What was the fatigue related to though?
   - Moderate to bad day – no talking, just observe

550

- o Experience it through someone else's eyes
- o Nothing else for the day if bad
- o Need enough rest
1. Yes visit again
2. Fairly standard – going to someone's house
3. Museum in Dublin – how they display humans remains
    1. Warning ahead of time – info outside the room, no info with the body itself (it's a body, not an artefact)
4. Yes – expect more from paying
    1. Should be relevant to the time spent
    2. Based on the worth
    3. Treasurer's HouseE was more than expected – student rate?
5. Situationally determined
    1. According to the government and 'official' diagnosis
    2. Depends on the day
    3. Something is disabling me
    4. Not an adjective
    5. PwD – not always disabled
    6. Constantly disabled by _____
    7. Have a Disability moment each day
- Prefer hand dryers – little bit of a warm up
- Take hand dryers out of accessible toilets?

# 5. Ellie.

## 5.1. Pre-visit interview.

- Migraine
    - o Longest diagnosis
    - o Dizziness – inner ear, motion sickness
    - o Visual problems
- Fibromyalgia
    - o Constant pain – joints
    - o Knees especially – uses a stick
    - o Fatigue
    - o Brain fog
- Anxiety/Depression
    - o Hand in hand
    - o Easily stressed
    - o Difficult to get momentum going
    - o Very draining
    - o Mental battle
    - o Constantly in the background
- Fibro – 'traumatic' event to start it
- Migraine, mental health – had her entire life, but aggravated by uni
- Have to carry lots of stuff at all times
    - o Lots of accessories
- Allot a lot more time to do things – uses the spoon theory
- Migraines make it difficult to use computers
- Types of lights are migraine triggers
    - o Have to avoid certain shops
    - o Fluorescent strips are not great
    - o Low flickering – incredibly sensitive

- - - Do others notice?
  - Trip prep
    - Uses google search for ideas
    - Use their website
      - Opening hours
      - Events and exhibitions (avoid children-aimed events as those are loud and busy)
      - How to get there
      - Feel of the museum
      - Costs
    - Screen reader (mostly for documents though as websites are BAD)
  - Easier to risk a migraine
  - Packs:
    - Painkillers, anti nausea
    - Water
    - Walking stick
    - Snack in case of migraine or fibro attack – need sugar
    - Phone in case of help
  - Takes about 5-10 minutes – already packed normally, part of the daily routine, not really museum specific

## 5.2. Site visit.

- Collapsible walking cane
- No temperature control
- Related to fibro
- Use back door because no steps
- Tag system for prams
- Squinting at the light
- Back lighting
- Can't read that sign
- Uncomfortable
- Bit too big, bit too heavy
- Bit awkward to handle
- Like that there are multiple ones
- Images and text are a good combo
- Quite obvious too when you walk in
- Struggling to take the words in but it's going straight out
- More of a brain fog and distraction thing
- There is a quite chatty room guide that's a bit loud
- Ghost mention 1!
- Lots of info but can skim through it
- Presented nicely in terms of how the information is laid out
- Even with a cane, no one pointed out where to sit
- Taking it quite slowly
- Meandering towards the sign holder thing
- Happily glancing through all the panels
- Quite busy today actually
- 8 people in the first room, 6 people in the second
- Good lighting in the great hall – bright and atmospheric without being artificial or too dark
- Struggling with the lights in the sitting room
- Very intense light in a small bulb
- Windows are shuttered now so it's a bit darker
- Blue drawing room is the name of this room

- Small but intense light
- Hard to transition from the corridor to the blue drawing room because of the light difference
- I just really like that touch
- Guides are very much interacting with the older visitors, kinda just nodding at us
- William and Mary staircase chat
- Change in the light level is hard to adjust
- More consistent lighting would be helpful
- Really struggled with the drawing room
- Changing light is just tough
- Consistent internal lighting would make it easier to enjoy and read
- Mildly disappointed in the lack of history for the object (see above photo)
- Pretty but also makes it difficult to actually USE the banister
- Talking about the deafness of Queen Alexandra
- And how her younger daughter stayed with her, likely as a carer
- Never less than 4 people BESIDES US in a room
- Def eavesdropping on the room guides
- Another mention of Queen Alexandra and her deafness
- Flat out said Zeus raped Leah
- In those words
- Which on one hand is accurate
- On the other hand trigger warning omg
- Upstairs is better
- Easier to navigate
- Feels clearer
- Has a focal point in each room with a bed, makes it easier to move around
- Finally had a room guide speak to us but we were also the only ones in the room
- Bahaha though the little old lady is arguing that the tray doesn't look like a tray
- Definitely TRYING to be interested
- Ellie moved in on a conversation instead of asking and the guide took the hint
- Not an official flow
- Not sure if like it or not
- Feel a bit lost and rudderless
- Need to make sure the garland isn't tied AROUND the banister but rather TO the banister
- Some confusion over the layout from another group of visitors
- Finally spoke with a room guide!
- Once again the room guide is taking the lead and not waiting to be asked, instead just talking
- Yessssssss got a question in
- Asked about the wallpaper
- Decoration painted directly ON the paper
- Low light for the textiles
- Very interested in the textiles and the needlework
- WOW interested in the textiles
- Can tailor your own experience
- Still haven't seen ANYONE sit in the acceptable chairs except for the lost houses room and the obvious settee in the middle of the room
- Feels like a good point to take a moment and just ponder
- Nice and neutral, nice stopping point
- Someone sat on one of the benches again in the neutral hall
- Again saw someone sitting on a wooden bench in the cellar

- It's clearly a seat you can use
- Ellie finally sat – took the headphones off
- Just watched the video partially
- Bit of confusion about where to pay for things but it was handled efficiently and nicely

## 5.3. Post-visit interview.

- Already knew where it was – initial sign helped and then it was easier after
- No green metal street signs
  - Actually, there is (INSERT PHOTO)
- Fairly easy – Christmas market crowd
1. Yes
2. Yes
3. Not realy – bit more guidance, especially up in great hall upstairs
4. No – "please pay upstairs" sign – no way to get attention
5. Yes
6. Yes
7. Ffairly
8. Could have been better
9. Ditto – hard to find the light switch – dark immeiately on entering
10. No
11. Yeah – room guides
12. Yes
13. Once the theme were understood, it was good – maybe needs an intro board?
14. Yes
15. Yeah
16. Roman – really loud
17. Panel – yeah
18. Little noisy – first fireplace room
19. Fireplace room
20. Never!
21. Not good – variable
    1. Conservation, sure, but CONSISTENCY
    2. Natural vs. artificial
22. Blue Drawing room – intensity of light
23. Blue Drawing room – too intense in small bursts
24. Not in downstairs in Great Hall
25. Needed more light to be sure
26. Yes
27. Yes
28. Yeah
29. Good
30. BAD
31. No
- Quite achy – short walk, then stand over and over – tough on joints
- Blue Drawing room – migraine trigger potential
- Difficult to curate the multistrand narrative
  - Pick and choose your levels of engagement
  - No obtrusive sign boards
- Lighting
- Quieter space – nice decompression space (sensory space) – intentional?
- Decorations on banister
- Options for visually impaired – not offered on arrival – only one method of presenting info

- - Physical accessibility
    - Understandable, but how to mitigate?
- Not really provided access tools
- Needs an audio element
- Multisensory is really important – balance between text and image (some boards were super text heavy) – think about how people move around museums
  - Didn't realise there was anoter staircase in the Great Hall at firsst
- Used walking stick
- Really nice room guides, welcoming, admissions too
  - Felt like a bit of a nuiscence in the shop – seemed impatient
- No
- Possibly not – maybe at a ticket desk if needed more help
- Yeah – when less brain foggy
- Lighting – makes a big difference
  - Reading can get very tiring very quickly

## 5.4. Follow-up interview.

- Really exhausted the next day – quite surprising, didn't expect to be that tired
- Lighting is still a bit issue – quite prominent
- Lighting was a bigger thing than the fibro – longer lasting impact
  - Could have a seat if super necessary, but can't do anything for a migraine
- Fibro biggest impact – physical aspect
  - Stop and go is hard
  - Used to movement but the change in energy and momentum is hard
    - Hips and knees especially
- Slightly too big on the handheld panels – design and content and intent were spot on
  - Surprisingly heavy – size related?
- Decorations – not a HUGe thing but a potentially big issue
- Don't tend to check accessibility guides
  - Look more at photos to get a feel
  - Basic overview on the admissions page tells her what she needs to know (wheelchair accessible throughout, etc)
- Tapestry room – revisit just for that
  - Without the christmas decor though
- Reminded her of Temple Newsam – mixture of period rooms (Tudor room, later periods, change between eras)
  - General stately home experience
- Changed going upstairs – would have just skipped that on a bad fibro day
- Migraine – would have avoided the Blue Drawing Room
- Anxious – would have avoided interaction with the room guides
  - Not too bad on the day
  - Normal expectation of nervousness
- Yes disabled – taken a while to accept
  - Identifies as a person with a disability
  - Not a conscious thing
- It's the little things – Leeds City Gallery has lots of interactives and different senses engaged

# 6. James.

## 6.1. Pre-visit interview.

- Everything hurts
- Conduct condicitis – tendons in the chest inflamed – can't move
- Comes and goes
- Variable
- Today is a medium day
- Planning – some days of nothing
- Spoon method – grade your actions accordingly
- Work has been understanding – moved to less movement position, cushion, touch screen pen
- Changed method of transport
- Batch cooking rather than every night
- Little things like that help
- Alexis – turns on lightswitches
    - Wifi lightbulbs
    - Voice control things
- Thought it was just age – until diagnosises
    - More and more time off
- Couldn't understand why the pain
    - No test for it
    - Have to eliminate everything else (MS, arthritis)
    - Added stress 5-6 years
- Gillian Tilsey – off on full pay, full hours
    - Felt good at the time, even if it's the law
- "Gee, what CAN I do as a Viking?"
    - Scared of losing job
    - Work has been amazing
- Health-wise is helping to control
- First of all okay – just cancel plans if pain is too bad
- Depends on the size of the museum
- Mentally prepare for it and deal with it
- Like to be surprised – not a lot of research beforehand
- Familiar with York – know what to expect
- Sometimes changes throughout
- Uses a stick
- Not a lot of planning – use a smart phone – good support structure
- Not long to get ready
- Depends on pain level – nothing significant, about 20 minutes

## 6.2. Site visit.

- No handrail
- QUITE a fast walker
- No obvious accessible entrance
- Having a quick look around
- West sitting room is the fireplace room
- Ghost mention 1!
- Asked for a bit of an intro from the guide, good overview of the history of the site

- Uh oh my battery is going fast
- Ghost mention 2!
- Noticed the sittable chairs
- Noticing the chairs in each room
- Held onto the columns to help himself up the stairs
- Nice and flat but also hard to find a seat
- Already feeling a bit weak in the legs
- No real flow to the house
- Mentioned banister
- Sat down in the Princess room
- Room guide walked over with us to speak
- Room guide wearing a cardigan
- Bit colder than last time
- Bit busier but not as much as last Friday
- Another room guide with a coat on
- Likes these chairs quite a lot
- Room guide has a torch and a buzzer around her neck (not sure what the neck thing is)
- Might be a portable hearing loop?
- Used the torch to show the tortoise shell in the cabinet
- More of a looker than a reader, prefers to chat with the room guides (how he learns? How he's trained at JORVIK?)
- Another room guide with a coat
- Last room guide had a gilet
- Nice an level floors
- Good to have these available at the beginning

## 6.3. Post-visit interview.

- Disabled access more clearly marked
- Bus – stonebow then walk
1. From the street, yes – in general, not really
2. Yeah
3. Not at all – no flow
4. No
5. Yeah – not busy
6. Yeah
7. Sort of – signs
8. Yes
9. No
10. No
11. Yes – are ou okay, be careful – Queen's room
12. Yeah
13. Not much reader
14. n/a
15. n/a
16. Fine
17. Yeah
18. Fine
19. No
20. No
21. Bit low – understandable

22. No
23. Queen's room – needed a torch
24. On the whole but a few not obvious and guides were pleasant
25. Yes
26. n/a
27. n/a
28. Yeah
29. Fine
30. Bit low but fine
31. Can't remember – probably not
    1. Probably not enough for a busy day
    2. Feel wrong taking a seat from another (more obviously) disabled person
32. -
    1. Volunteers – very engaging, very friendly, on it
    2. Lack of handrails – pretty but impractical
33. -
    1. No trip hazards
    2. Handrail
34. Handrail – SUCH a bad idea, huge impact
35. n/a
36. Little seats we saw in show
37. More hand grabs/ hand rails, something to hold
38. n/a
39. Welcome
40. n/a
41. Probably
    1. Feel/hope more offers of sitting
    2. Even a stick is more visible
42. Handrails!!
    1. Layout – confusion
        1. Direction, concentration
        2. Brain fog

b.      Seat on landing

## 6.4. Follow-up interview.

- Achy, expected levels
- More chairs, especially during summer or high volume times
- JVC – chairs to take around
- Chocolate story
- Yes – pay – more expectations
    o Don't agree with non-paying
    o Charitable donations
    o Paid for – income
- Not done with stairs
    o Chair lift? Ways around it
- Barley Hall tablet
    o VR – more immersive
    o Interactive way of exploring
- Funding is always an issue
- Some kind of scheme – help poorer (social inclusivity)
- Maybe children are free? Tricky balance for income vs charity

# 7. Jessica.

## 7.1. Pre-visit interview.

- Dyslexia – learn in a different way, spelling, reading, homonyms
- Irlens Syndrome – light sensitive, harsh lighting
- Lots of text is tough
- Colour overlay
- Software – read texts on a machine – good for editing/proofreading
- Didn't get diagnosed until last year
- Just need extra tools
- Sad at first, but relieved now
- Preparation
    - Context of museum – scaffolding for herself
    - Videos are helpful – audio is better to learn by
    - Youtube, podcasts, documentary
    - Audio guides – no extra cost is best
    - Learn better through audio
    - TripAdvisor – see when it's less busy
        - Wants to take more time, and will feel less guilty about doing so
    - Headsets can be TOO popular and have queues, which puts her off
    - Treasurer's House
        - Headsets
        - Website is hard to navigate
        - Not a lot of good info on the House itself
        - No audio guide but saw headsets
        - Wikipedia was good for background info
        - Uses youtube for videos, but there were none on Treasurer's House
        - Read aloud for info
        - TripAdvisor – actuallly has lots of access stuff, good to learn about the atmosphere
- Colour overlay – on laptop
- Pocket size overlay
    - Embarrassed using it though
    - Backlighting on panels is HORRIFIC
    - If it's too busy or not accomodating, not a long visit as it's not engaging
    - Headaches are a thing – passed out from harsh lights before
- About 20 minutes of research per museum
- Keeps notes about museums for longer trips on phone – up to an hour of research for longer trips

## 7.2. Site visit.

- Start from her flat
- Using Google maps
- Made it
- Reminds her of a place she went to in Barnley
- Looking at a card
- Quite dark
- Colour of the card is quite nice because its ivory
- Really weird font on the pull out cards
- Really hard to concentrate

- Off white is good
- Image isn't in between the text
- Bold doesn't help with reading
- Underline instead?
- But she is looking through all the pull out cards
- Standing near the stand though
- Light is quite dim
- Reading through the cards
- Glancing through, reading the starts of paragraphs but lighting isn't helping with concentration
- Light is shining on the laminated sheets and making it impossible to read
- Lots of bold and italics
- Wouldn't bother reading
- Probably just go home and read more about it
- Natural light is nice
- Doesn't look too overwhelming
- Would read it online
- The numbers are helpful
- Numbered pdfs?
- Download it to your phone
- Could read it in her own time
- More engaging
- Overlay helps to keep place when reading too
- Overlay is much better for stuff that is picked up
- Like my own personal text panel
- Too many colours now
- All she can see is the white, very distracting
- Asked about the lighting in the sitting room – conservation and energy
- Good explanations
- Nice and chatty, comfortable and easy with her
- Very personable
- Natural lighting through the windows is very nice
- But it doesn't extend too far in
- They keep it dark for conservation reasons but also to recreate what it would have been like when Frank Green was here
- He didn't have electricity, only candles
- The Sheen of laminated stuff is just awful
- Also looks so tatty
- Needs clean layouts
- Not pics in between text blocks
- Instead of bold, larger font? Less thick bold?
- Borders instead of different background colour
- Difficult to differentiate between sittable and non sittable chairs
- Lighting in ship room is really hard to see
- Some confusion over route
- Quite heavy
- Text panels
- Balancing with the overlay is quite tricky
- Audio??
- Nothing about the weird table on the panels

- Reads well outloud with her overlay
- Only one small swap of words in the last sentence
- Room guides were chatting with someone who likely had down syndrome and they were very patient and welcoming
- The steps in the garden were too hard for him
- Text is in chunks, so it's not so bad
- Wouldn't be able to put overlay on that, but doesn't really need to either
- Kngs room is very dark
- Alt text on the images is greatly appreciated!!!! Her screen reader picks them up
- A lot lighter in the last room, easier to read the text on the wall
- Sat down for the first time, it was obvious she could sit?
- Good lay out, enjoyable to read, nice and bright, doesn't need the overlay for this
- The cream is quite nice
- The brown text is easier to read
- Brown is more enjoyable to read than black text
- Example above – very small difference, but it IS a difference
- Darker in the corridor so it's harder to read
- We aren't the only ones confused about the route
- You don't need to put quotes in italics if they're already in quotation marks
- Immediately drawn to the video in the kitchen
- Leaned in to read the newspaper text on screen – was it long enough?
- Yes she could read everything in the video just fine
- With captions!
- Absorb info better with audio
- A nice break from so much reading, it's easier to learn
- In the shop, mostly aimed at adults
- Lots of gardening
- Cute for Brenin and Rhiannon
- Stood at the till for a moment, needed to get the lady's attention
- She was very polite and nice and was working on arranging things in the shop, less pressure to buy on the customers
- QUITE dark in the dining room with toilets
- Confusion on how to get back out

## 7.3. Follow-up interview.

- Still hate the lighting
  - Huge issue
  - On a bright day but still tough
  - A dark day would have been awful
- Great staff
  - Above and beyond
  - Really lovely
  - Good alternative to reading
- Hand held, personal panel
  - Less obtrusive
  - Silver lining to the whole thing
- Too difficult to revisit
  - Would do own research instead of revisiting
- Gorthorpe Hall

- o Similar lighting
- o General issue with manor homes – see Castle Howard
- o No modern additions
- Minster Undercroft
  - o Lots of light
  - o Interaction
  - o Hands on
- North Macedonia – Holocaust Museum
  - o Modern
  - o Different interactives
  - o Emotional
  - o Immersive
  - o Do the reading in different ways
- Liverpool Maritime and Slavery Museum
  - o Lots of senses
- Lots of different ways of presenting info
  - o Listen, see, do, read, watch
- Paying expected to be better
  - o Non-paying, lower expectations
  - o Paying for a service – needs to be a meaningful experience
  - o Bit more lenient for lack
  - o Perhaps not meaningful at Treasurer's House
  - o Online resources, audio guides
- Dark day, headache
  - o Bad day
  - o Probs wouldn't have changed much
  - o Even at the brightest outside, probs still wouldn't be enough
- Disability SPECTRUM
  - o Not that bad
  - o Don't have the "right" to use the word
  - o Needed disability help – compared to peers
  - o Don't put it on job applications
- People with disabilities – overt word

# 8. Kasi & Teagan.

## 8.1. Pre-visit interview.

- Postural Tachycardia Syndrome – comorbid with EDS
- Kasi – ADHD – spacing out a lot
  - o Needs verbal information
  - o Gets lost very easily
  - o Right and left are confused
  - o Can't remember directions
- Colour coded maps are helpful
- Trip prep
  - o Teagan – uses a tablet
  - o Kasi – needs to know where bathrooms and food are
  - o Looking at the time
  - o Abbey HouseM site – no time on the access page, wants a layout of the museum
    - Wants how to get there on the access page
    - One handed typing

- - - Wants bus info on access page
      - Embedded maps
      - Again, wants site layout
    - Turns off bluelight on tablet
- Canes? Mobility aids – braces (took pictures)

## 8.2. Site visit.

- Compression socks
- Didn't check bus times so walked to train station
- "DO YOU HAVE TO GO PEE ALREADY"
- Lift out
- Had to run to catch the next train
- Carried stroller up and down stairs
- Apples and peanut butter and Nutella for snacks
- Brought water bottles
- Organisation : use folders for each of the three meetings, will hold things better
- Maybe folder for each participant?
- Laminate instruction sheets
- Wrong train tickets – missed first train, caught one five minutes later, conductor didn't care (possibly because baby?)
- My temp access needs: anemia, both symptoms and medication
- "recording shirt" with pocket
- Showed wrong ticket, conductor didn't care. Definitely the baby
- Really hard to not jump in and help, either physically or with suggestions
- Toilets at station out – person at desk told us to use some outside
- Signage for toilets outside was fine but inside was a bit of a nightmare
- Bus wardens were mindful of "if you're able to walk another five minutes, this will be helpful"
- A MESS of bus stations outside, there's work going on
- Not many noticeable employees inside, but outside there was loads
- Bus arrive about 1025
- Reeeeeally sketch item in gift shop
- Automatically got the gate for us because stroller
- Helpful when asked a question
- Mostly flipped through interpretation to look at pics
- Blinded by that – a spot light
- Spent more time looking at the book of ONLY pics (portraits of the time)
- Paused at the café to feed Annora
- Woman was very helpful
- No name tag though
- Man it can get BORING following them around a museum
- Though it's likely because Annora is slowing things up
- 11 stairs
- Level throughout Upper story though
- Lots of seating in almost all exhibits
- No name tags on anyone
- Steady but not busy, probably 20-30 other people in at the same time
- Someone pulled the cord by accident and the person responded quickly, though there was an air of "here we go again"
- But also it was just a dad with his kids doing a nappy change
- Annoying that nappies must be disposed of in the accessible toilet
- But they do call it the accessible toilet so there's that
- WELP I dropped my booklet somewhere, that's okay, I think I can rebuild a lot of what I said in there from memory

- Yeah I def need a new phone battery especially for my visits to Leeds
- 920 train 1020 bus 1045 museum
- 1430 bus
- 1330 pub lunch
- It is definitely time for my nap
- Follow up questions : one thing to tell museum still the same, still wouldn't really return, more confirmation questions
- Kasi toilet – at train station in Leeds, leaving museum
- Estimated time spent on website
- Good for planning around naps
- 1524 train

## 8.3. Barley Hall follow-up.

- Changes
  - Didn't cater to kids anymore – especially the upper level
  - Flow of ground floor worked
  - Not missing anything in closed off areas
  - Lighting in lower chamber WAY too low
- Map
  - Boxes on map – font/colouring was a bit hard to go between black on white and then white on black
- Sudden turns are hard on the hips – but removing the table would make people pass right through
  - Angle the table a little?
- Liked the new front area – felt like you could stop and watch the film rather than sort of being in the way where it was before
- Height of the thresholds – mandated height?
  - First two are VERY high
  - Mitigate it somehow? Half step? Rope to hold on to?
- What's the point of the garden?
  - Are the listed plants all there? Are they different plants?
  - Rearranging heights if you want people to smell them – bending over is hard for some people
- Foyer
  - Seems like a wasted area
  - Light projection? Touch screen?
- Parlour
  - Light was good – about as low as you should go
  - "Cluttered by not cluttered" – good level of stuff in there
- But it did seem like they put the most stuff in the smallest rooms
- More magic on the tables in the Great Hall – spread the exhibition out a bit more
- Lesser Chamber
  - Too dark for that amount of reading – especially with the objects
- Bit jarring entering the gift shop – going from nothing to everything
- Put the dreams bit in the parlour? Is the parlour meant to be magic or realistic?
- External handrail – too rough on one side, need to add one on the left side
- While we were there…
  - Sarah called reservations to handle an upgrade ticket – she had the agency to say "hey I don't know how to do this" and Paul allowed her to contact Res to learn how to do it

- James had to turn away some walk-ins because of limited numbers; he explained the situation, that it was due to COVID restrictions, and they were very understanding and okay with it

# 9. Lisa.

## 9.1. Pre-visit interview.

- Medication for it – 3 years
- Social anxiety
  - Can't just go out
  - How I look, how to get there
  - Planning to the extreme
  - lots of extra time
    - Or mega late due to attack
- Cancel plans a lot
- Don't always up the real reason for cancelling
- Migraines
- Don't always go out especially in the evenings
- Post-natal anxiety
  - Like routine
  - Bedtime routine especially
- Lots of googling
  - Location
  - Time to arrive – plus extra
  - Parking – parkopedia
  - Clothes
  - Change, petrol
  - Photos of the inside
  - Street view
  - Menu
  - Inside locations
- Facebook – museum pages
- Googling – see what comes up
- How many floors
- Where they recommend to park
- General info
- Not usually access page – wouldn't search it out
- Phone – fully charged
- Prepare for traffic jams, earlier buses, loo trips, good (need a quick bite if wobbly)
  - Need to know where the nearest loo is
- Start planning immediately – watch google maps for timings "just in case"
- Not weeks of planning, but a little bit each day for weeks
- For work, it's no problem
- For personal, probably wouldn't go – too much emotional investment

## 9.2. Site visit.

- Lovely interaction with staff
- Fsr more staff here today than last time
- Legs are shaking
- Been around a lot of times but still have nerves?? Different hat on now
- Lovely Christmas stuff out

- Objects in a shop
- Looks at the objects
- Looks in detail but as soon as someone else comes in, that's it
- A bit claustrophobic if there's other people in the room
- 
- Looker rather than a reader
- Anxiety – doesn't like to linger in one place too long
- Pick up and carry card – would totally read it
- Watchdog programme – how fast children's clothing goes up in flames- scared since then
- Doesnt like too crowded – could they put hours for less crowded times?
- Yeah definitely a looker, we are BREEZING through this museum. But is that related to familiarity?
- Loves looking at children's toys
- QUITE a lot of mums and toddlers here today
- Also a teachers group
- But pretty quiet overall
- He she them is their community gallery
- Still have the sign but not nearly so in your face
- Cragside – first country house with a specific kind of lighting
- Try to avoid hand driers because son doesn't like the noise
- Can't always plan when anxiety will pop up
- Might have chronic fatigue too

## 9.3. Post-visit interview.

- Car – have trouble finding the car park
1. No – don't know that's the museum
2. Depends which direction – shop
3. No
4. No – difficult where to go from there
    1. Pricing is clear
5. Ideally – okay if just a few people
6. Yeah – back bit with books
7. Yes
8. Yes
9. Yes
10. No
11. Yes
12. Yeah – friendlier museum, smaller
    1. In touch with a lot of staff, lots of presence
13. Victorian street – lots of little things not signed, need loose info – purposeful
    1. Upstairs – He/She/They engaging signage
14. n/a
15. n/a
16. n/a
17. Yes
18. Generally good – as soon as groups show up, out of there – didn't even want to linger with a group of kids
19. Groups were loud
20. No
21. Good – like less bright, artificial, more atmospheric
22. Stairway quite bright
23. No
24. No

25. Not necessarily clear or obvious
    1. Pharmacy – want a bit more info
26. n/a
27. n/a
28. Yeah – overall theme
    1. To avoid group
    2. Wouldn't go to school room because of group
29. Quite echoey, loud
30. Dim – not that much importance
31. Little bit more, more obvious – nowhere to really sit
32. -
    1. Victorian street: immersive, intriguing objects, momentos, info cards
    2. Child death – important, but not appropriate, more thought into the presentation?
33. -
    1. Lift, toilet, ramp – certainly put physical access in
    2. Layout – not very clear – maze to get to the entrance from the shop
34. No signs towards stairs?
35. n/a
36. Map – usual route
    1. How to get to street, stairs, where it brings you out
37. More hand out sheets to pick up and read
    1. More likely to READ not scan
    2. Not pushed to keep going, more lingering
    3. Signs for exhibitions and that they're temporary – seem to be just a new thing
38. n/a
39. Welcomed, quite lovely
40. Only in that they knew you – always friendly
41. Yeah – physical – offer help, asking if need help – more "on it" – not in a bad way
    1. Probably wouldn't know it's a panic attack – drink, sit down
    2. Would just leave instead of asking
        1. Would accept help
        2. Depends on level of help needed

Sure would
Don't presume everyone is okay, always ask visitors if they need help
.    Consider signage – quite used to it but look at it with fresh eyes
- ~1-2 hours
    o Plan particular times for less crowds
- Encourage it for other people (autism hour)
    o Don't want to take away from the people who need it

## 9.4. Follow-up interview.

- Don't assume everyone's fine because no visible disability
- Consider signage – need fresh eyes
- Would return
- Victorian Street
- Next day – tired
    o Panic attack that night
    o Spoke with husband, got feedback, acknowledgement
- Missed out bit because it was busy – planning
- Space issue, not the noise levels
- York Castle Museum – Victorian Street
- Eureka – kind of museum, surrounded by STUFF
- Cantigny Park

- JORVIK ride
- Expect more when paying
  - Leeds City vs Abbey House
  - More in Leeds city
  - Experience
- Could have gone on a bad day because of familiarity
- Not disabled – interesting

# Appendix E – Field Diaries.

This appendix contains all the field diaries that were written throughout the course of data collection. Field diaries were written after meetings with participants to allow me a more reflective and reflexive way of thinking about our interviews and site visits. They are arranged alphabetically by participant's name – except Teagan and Kasi, who are listed together.

## 1. Aaron.

### 1.1. First meeting.

Aaron is an interesting character. A lot of his answers seemed rather rambling and I didn't always follow how they related to the question. I will need to go back and re-listen to follow the logic. He also was extremely fatalistic about basically everything, but I think it'll be good to have that point of view as well. Not everyone has to be understanding nor kind – it does make me wonder how fast his BPD cycles are, as you can almost track the rise and fall of his mood.

## 2. Alfie.

### 2.1. First meeting.

I thoroughly enjoyed meeting Alfie. I'm really interested in exploring the intersection between his dyslexia and his vision, particularly as he has limited depth perception. I really enjoyed going around and checking the different labels with him – it was fascinating how things like margins impact how well he can read. But also, the fact that everything is so text heavy is really surprising, even though I've been through Barley Hall countless times. I just never realised it before.

## 3. Amanda.

### 3.1. First meeting.

Amanda was a very lovely participant. She definitely spoke her mind and wasn't afraid to be overly harsh about certain aspects of the visit. At the same time, she also didn't hold back on herself, admitting that some of her own foibles and the fact that her pride is keeping her from getting more visible help for her disability.

At the same time, she represents a very different type of museum visitor. As she said, she likes to go to places that have a 'star item' – but none of my case study sites really have one. They are more about providing an experience, an atmosphere. She likely would have preferred a more traditional, white box with glass cases kind of museum.

You could certainly tell that she was getting more and more tired as the visit went on, and a few times she simply sat on one of the benches and just closed her eyes, breathing deeply. It was unclear if she was simply relaxing or taking a moment to control her pain. I didn't see

her take any pain medication, though she did have both that and water on her the entire time.

There was a bit of confusion in the shop when we left. The tea towel that she wanted was incorrectly priced, and the admissions staff was a bit perplexed, so she had called in the duty manager to help sort it out. Amanda started talking very loudly to me about her experience working in a charity shop where a similar thing happened, and how she handled it by just using the lower price and dealing with the problem later. While that is what eventually happened, she was clearly bothered by the whole situation. The entire interaction lasted a maximum of two minutes, from the moment she approached the till to the moment she was given her purchase and receipt, and there was no one else in the shop, but it was a sore point for her. She did say that everyone was helpful and lovely, though perhaps they could have dealt with it more efficiently to prevent embarrassment.

I also think she might have an undiagnosed learning disability like dyslexia. She had problems reading the signage, and when pressed, agreed that it wasn't the size of the font. She suggested using a different font, or a different colour scheme, both of which suggest dyslexia to me. She also said that the letters were blurry or bouncy to her, which again suggests dyslexia. Given that she is in her 60s, she likely wouldn't have been diagnosed with it as a child and had to make her own accommodations to deal with it herself. It's very possible that she doesn't even think she had any learning disability, as this is how she's been her entire life.

Overall, the visit went really well. It was quite chilly and damp on the day, which was affecting *me* and I can only assume was affecting Amanda all the more. I think I need to make sure that the front of house staff member is instructed to ignore me, as I think her interaction with the admissions staff was slightly different than it would have been for another visitor. I don't believe it made a big difference, but I want to make sure they receive an authentic experience and not one that is challenged by my presence.

Also, there was a SEND school group in while we were. The ramp to the Great Hall was set up for them, and we were warned that they would be eating lunch there shortly so we should walk around it before they went in there. They were well behaved and I didn't get a chance to see any staff interaction with them. Natalie did show up at one point, but I don't know if that was related to the group or entirely coincidental.

## 3.2. Second meeting.

Amanda definitely represents a different type of museum visitor than most of my other participants so far. She was far more focused on 'star objects' – artefacts like the Middleham Jewel and things like that. I think she would feel more at home in a traditional white box, glass case museum, rather than the type of sites that I'm studying in this research. This could be another avenue of research for the future, as all of my sites are more immersive and experiential. However, I believe that a lot of the findings from this research will be equally applicable to those traditional museums as they are to my case study sites. It would be interesting to see if there are any specific accessibility issues related to the traditional museum layout – again, perhaps a future avenue of research.

Talking with her more, it was now clear that the lighting was more of an annoyance than a true hindrance. However, I would still recommend revisiting lighting in some of the areas, particularly as the lighting in places like the pantry and buttery makes them uninviting to visitors. Also, if a place has written text, it's vital that there are places with enough lighting to

read that text. Someone in a different interview mentioned spotlights on text panels as being helpful and a good compromise for conservation concerns – but also being able to pick up these interpretation panels and take them to an area with better light is a good shout, as Amanda pointed out.

Her views on paying vs non-paying are REALLY interesting, as she put more expectations on the non-paying museum, whilst all my other participants so far have said the exact opposite. But I understand her logic – non-paying ones tend to be National museums, and also have external sources of funding, which then makes them seem better connected and financed than paying museums. I can see this being a generational difference, given that Amanda is older than my other participants so far. I'll be interested to see how this trend continues in the future.

# 4. Amy.

## 4.1. First meeting.

Amy is an absolute delight. She has more trouble with mental health issues than physical issues, I believe, but that's partly what makes her insight so crucial. I don't know the statistics off the top of my head, but my instincts say that more people are diagnosed with a mental illness now than a lot of chronic illnesses. It's certainly a very prevelant thing, and knowing how to make museums mental illness friendly is going to be HUGE as we move forward. Also, it's very heartening that she too is a heritage student, and that a lot of these access issues, she's already thinking about.

Our visit was very nice – there were a few times she needed to sit, and it was quite clear that there wasn't necessarily a place for her to do so (not obviously at least). She was very interactive with the room guides, and was very upfront about her disabilities, despite them being invisible. It's also helping me immensely in talking with her, as I have a similar set of mental health issues, and I've been struggling with whether or not they were disabilities. But the very fact that I do have to take medication in order to manage them proves that they have a significant, negative impact on my life, and therefore they're disabling.

I find it really interesting that she liked the lower light levels – she's right that it adds to the ambiance, especially in the Blue Drawing room which is supposed to be just after a party. But also she wasn't relying on written text, which she also admitted would need higher lighting levels. Finding that balance is going to be really interesting.

## 4.2. Second meeting.

Amy has been really insightful throughout the whole process. She's very aware of her disabilities and their impact on her, and also how to manage them and the world around her. This has meant that she also has a lot of insight into how different places can adapt to increase their accessibility, as well as the problems inherent with it.

It also sounds like she has an amazing support structure around her – she and her friends discuss accessibility in normal conversations, which is amazing. Their insight into removing loud hand dryers from accessible toilets doesn't solve ALL problems, but it would certainly cut down on inaccessibility.

It's very interesting that the banister is still something that bothers her – but it's much more the meaning of it than the detail itself. It's the fact that no one really thought the decorations through, that they simply assumed people wouldn't need to use the handrail AS a handrail and not just as a decorative thing. This was actually borne out as I went around on multiple visits, as I saw a number of visitors go to use the handrail and pull back when they touched the decorations instead.

# 5. Ellie.

## 5.1. First meeting.

I'm really really glad that I've chosen Ellie to go to all 3 sites. I think she'll have some amazing insights and experiences to share. Also, her variety of disabilities – all hidden, but fibromyalgia does have a visible aspect with her stick sometimes – make things really interesting and show the wide range of accessibility options. She's very quiet, which I think is much more to do with her personality than her anxiety, but she seems very comfortable around me. I'm really looking forward to building that rapport with her, and also revisiting some of her earlier answers to the questions in these interviews.

Overall, our visit was fairly standard, as I'm coming to understand. Lighting is an issue, she didn't know where she could sit, the staff was very lovely – these are very common themes, although it's not necessarily across the board. However, it is showing that there are small little changes that could easily be made to make people more comfortable in the space.

I find it really interesting that the flow has consistently come up. People are slightly confused where to go – and not just amongst my participants – and skip some rooms entirely. This was something that Teagan and Kasi had flagged up, but I'm noticing that the need for directions or at least some kind of spatial layout is common amongst people without dyslexia.

The only really memorable moment that stands out in my mind is when we were paying in the shop, and there was a little exchange with the cashier. It was unclear where she should pay, as the café customers were paying in the shop, but the shop customers were being directed to pay upstairs. It very clearly rattled Ellie, and it came up in our interview as well. I'm not sure the system that's in place right now, but it's very confusing and needs to be revisited.

## 5.2. Second meeting.

One interesting thing that I asked Ellie was whether or not she checked access guides, and this is a question I want to start incorporating into my interviews. She said she didn't, and it actually surprised me. Then again, I'm very steeped in what access guides include (or should include) and have a vested interest in the subject. So far, no one has said that they actually check them. On one hand, this is a bit disheartening to me, given all the work I've put into ours, but on the other hand, it's understandable. The overall impression is that it's for people with severe, obvious disabilities, not someone who just wants to make sure there's enough places to sit. In turn, we need to make sure that we're incorporating passive accessibility things, like obvious seating and better lighting, rather than active accessibility things, like lifts or large print guides. Things that are just Treasurer's HouseERE are going to be more helpful than things that people have to ask for – Amy said something similar, that if she has to ask for something, she's unlikely to ask for it.

# 6. James.

## 6.1. First meeting.

James is a very interesting participant – he is not only someone with a hidden disability (fibromyalgia), he also has worked in tourism for decades and indeed, works at one of my case study sites. The fact that he understood the balance and tension inherent in accessibility in listed buildings made him very understanding of some limitations, but also aware that there were definitely areas that they could improve without much difficulty.

He was a surprisingly fast walker, though I'm not sure if that's natural or simply wanting to get to a place to rest as fast as possible. He was very engaging with the room guides – probably part of his experience in working in tourism and heritage as an interpreter himself. He had no problem sitting when he spotted a chair he could sit in, but he also sought them out when he entered a room.

He himself said he's very much a looker rather than a reader, and I wonder if that's because of preference or some undiagnosed learning disability. It's also very possible it's simply personal preference.

## 6.2. Second meeting.

I'm so looking forward to working with James again in the future – he will be one of the people I shadow at Barley Hall, so I'll be able to follow up on many different topics and any questions I have. He's been remarkably candid and open about his struggles and his opinions, and I'm really interested to see how he uses his experience as an employee in the heritage industry.

# 7. Jessica.

## 7.1. First meeting.

For Jessica, we decided to do the pre-visit questions and the visit itself on the same day, which actually ended up being an *amazing* decision and I'm going to recommend it to all participants going forward. The York visits at least shouldn't present a problem, but we'll play it by ear with the Leeds participants. It might be difficult for me to get to Leeds in time – but we'll worry about that when we get there.

Another thing that was interesting today was the audio recording for the visit itself. Jessica put the recorder in her bag, and listening back to the audio, nothing really was recorded. But the house itself was very quiet and hushed, as Jessica herself pointed out, so I'm not sure that would have made much of a difference. However, I had a feeling that might be the case and took as many notes as I could during the visit itself. But it seems like recording the visit itself isn't really necessary – I just need to make sure that I'm taking copious notes. Even during some read aloud moments, I took really detailed notes and can reconstruct what was said without a transcript. Also the visit took FAR less time than the pilot study visit, about an hour total, so that also helped with exhaustion levels. It was about 4 hours total, which was amazing.

It's interesting, contrasting Jessica with Teagan and Kasi. Jessica is quite new in her diagnosis and even fought against it for a while, whereas Teagan and Kasi have dealt with it their entire lives. Given that all three have dyslexia, it's really interesting to see how they've handled it well, and yet they all see themselves in the same light, especially regarding disabled vs PwD. All of them see themselves as someone with a disability, even though that disability affects the way that they read, which is a very significant act in our culture. I'm going to follow up with Teagan and Kasi about their use of colour overlays, as I'm not sure if Jessica' use of one was linked to her dyslexia or her Irlens or both.

I think starting my proper data collection with Jessica has been really helpful too. We're both comfortable with each other, and it's boosted my confidence even more in this whole process. I've had to reschedule three different participants now, which is rather disheartening, but I know that it will be fine. I have plenty of time to get these visits in, and as long as I get my Treasurer's House visits in before Christmas, I'll be in very good shape. I don't foresee that as being a problem, either, it's just a matter of persisting.

## 7.2. Second meeting.

Jessica and I met for our final meeting tonight – I admit, I was a bit tired, having come from a very busy day at work, but luckily, the meeting didn't last too long. It was about half an hour, and it was just going over the interview questions anyway. Jessica had somewhat prepared her answers, judging by how she presented her answers, but I'm glad that she had. A lot of these questions don't really require a gut reaction, and a more thought out answer is helpful. I also noticed that I was giving far less vocal feedback than I had with Teagan and Kasi, which will not only help with transcripts but also makes me feel like I wasn't dominating the conversations nearly as much. I very much want to put my participants front and center, and not talking over them is a crucial part of this.

Overall, I believe Jessica was an amazing participant, and I've gotten a lot of good data from her. There's lots of aspects of design that she highlighted that I hadn't considered before, specifically the placing of photos within text panels. If we want to encourage people to read our interpretation boards, we need to make sure they actually CAN read the boards, not simply glance at them and then decide they're too difficult to decipher.

# 8. Kasi & Teagan.

## 8.1. First meeting.

Overall, the whole thing took about 1.5 hours. It might have been a little less, as we got off to a slightly late start, and we had Annora interruptions every now and then. Each time she interrupted, however, it made me realise that I probably don't need to have an exact transcript of each part, as her little interruptions won't be relevant. It'll be interesting as I go to figure out what is relevant and what isn't, but for the start, I think I'll err on the side of caution and add in anything that isn't obviously irrelevant.

There was one comment that I made in a teasing, friendly manner that upon reflection, I probably shouldn't have, as in the written form it might come across as mean. Kasi had made a teasing comment about Teagan being dramatic in her accessibility needs, and I likewise made a teasing comment to Kasi, but as soon as it had left my mouth, I immediately felt like I had crossed a line. It took away my professionalism, even though I think of Kasi as an adoptive little sister. I don't think I should have said it, even though both of them laughed

it off, and I'm debating whether or not to keep it in the transcript. I think I need to keep it in, but emphasis the tone in which is was said.

I did find that Kasi was a little quiet and subdued at the start of the interview, letting Teagan lead most of the initial discussions. She did open up as the interview went on, and by the end, she was talking even more than Teagan was. I feel like there was a certain amount of unease discussing her disability at first, as if she wasn't used to people asking her about these things or was uncomfortable discussing them in an open manner, but the more I looked to her as an expert, the more she seemed to respond to that.

Also, I thought I knew quite a bit about dyslexia going into this, having done a decent amount of research for both this PhD and my masters about accessibility for people with dyslexia. However, I was quickly shown that I had only scraped the surface of what living with dyslexia was like. It was very interesting to see the interplay between EDS and dyslexia, and I want to follow up on that in one of our other interviews.

One thing that really surprised me was the insistence (perhaps not the right word) on how useful a map to a site was. Not how to get there, but rather how to get around. Even if it was a really basic one, showing where exhibits were and toilets and things like that, it would have been really helpful for them in the preplanning stage.

I conducted the interview in Teagan's living room. I sat on the floor, as I am quite comfortable in that space, whilst they sat on a chair and the couch. I felt that this positional authority helped Kasi especially, though Teagan and I have a very good friendship already and so we were very comfortable talking about her disabilities. Also, I know they have a habit of not turning on the living room light until it gets nearly dark in that room, and so I found it difficult to see as the daylight started fading. I also found myself spacing out a little towards the end, but I think this had to do with me being quite thirsty and not having any water on hand. For future interviews, I think I'll try to sit at a table with them and make sure that I have adequate light before we start as well as bring my own bottle of water.

For the morning routine walk-through, Kasi did physically take me through the stages whilst Teagan sat on the chair and explained it to me. It was slightly different, I believe, for Kasi, as she is staying in a different location than her home, but it still seemed like everything was roughly the same for her routine, just with spatial differences due to being in a different house. Teagan had mentioned that she had hurt her knee that day, so I didn't want to aggravate the injury any more by making her physically walk me through her routine. Plus, her morning routine is very regular, due to being a mother, and most of it revolved around getting Annora ready rather than getting herself ready for the day.

It was a bit tricky having two people for this meeting, especially when trying to get them to do the Thinking Aloud practice. I couldn't concentrate on both of them at the same time, and I didn't want to single one of them out at a time, so I drifted between the two during the practice. They did both seem to come to it easily enough, and I only had them practice twice. I think with future participants, it will really be helpful when there's only one person so I can give them my undivided attention, especially when I have limited rapport with them.

Overall, I think it went really well. I need to practice my transitions a little more, practice my "speeches" so that it feels more natural, but I didn't refer to my notes nearly as heavily as I thought I would, so I felt like I seemed more professional and more prepared than I

necessarily felt. I'll definitely be practicing my sections before I interview other participants, as I want to present myself as someone who is very interested in what my participants have to say, but also very prepared and has a certain amount of control over the interaction. I worry that if I just let them loose, it will seem like I have no idea what I'm looking for, but I also don't want strict control over every interaction. I think the way I have it set up now is good, I just need to put a little more practice in my sections to really nail down the tone and feel that I'm going for.

## 8.2. Second meeting.

So I definitely need to really think through whether the whole trip is worth it, especially to Leeds, as this was a VERY exhausting day. I think part of it was just how busy this month is and I'm also trying to pull myself out of anemia and that exhaustion, plus getting ready for Tanzania. It's also worth remembering that I only need to go to Leeds 4 times, and the rest are in York. But maybe a truncated version, as in not following them all the way back to their house. Something to consider, at least.

Overall, the visit was helpful, but I think more as a relationship-building exercise. I don't feel that I learned a whole lot from the visit itself, at least not things that I didn't already know. This may change as I examine other disabilities, but the café chat and the travelling aspect were far more informative than going through the museum itself.

Also, I'm really leaning towards doing my own access audit of the museum before I take participants around. I can still follow my worksheet, but it'll be easier to go through that on my own rather than juggling it with my observations. A lot of the questions won't change from visit to visit, and what does change, I can focus on more. I do want to add in things like the light meter and the audio reading, as well as testing out the Claro Pen scan app. I can probably also find some app that tells me font style and size, and I can more closely look for other access aids.

Writing my initial notes in Discord worked surprisingly well – it gave me time stamps and I could send quick little messages. I tried to open the journal app I had but it just wasn't working well for me. I really like making a note, hitting enter, and being able to start a new line where I can't mess with previous notes. So I might make my own server for privacy reasons and use that for my field notes.

I am glad that I brought both my plug and my extra battery, as I really needed it, so I'll need to get a better battery for my cell phone before I do my full survey. I haven't listened back to the audio yet, but I'm interested to see how my shirt worked with the recorder pocket. I also need to talk to Neil about making sure I have the cord that's needed to transfer the files straight to my computer.

I think I do have QUITE a lot of data though, lots of insights that I would not have gotten any other way, so I definitely think this is a really good way of gathering this type of data. I think there is more to tease out of the semi-structured visit – like I'm trying to do too much with it, and I need to focus it more or perhaps divide it into separate things, I'm not sure. It felt like it had lots of potential but I wasn't quite able to unlock it all. But that's what pilot studies are for, and I think this is a really good start to the whole thing.

Also I managed to lose my print out that I made for myself with my worksheet…. So again, doing the audit will probably be a good idea, and making digital field notes as well. Much harder for me to forget my phone somewhere.

I didn't want them to worry about writing or reading the worksheet I made for them, so I verbally went through it with them. Also, we had our food then, which would complicate things, and when I had given them the consent forms, they didn't even read them, just ticked all the boxes, so I felt it was better to go through the questions as part of the interview. I think I want to combine my outline and the worksheet a bit better so that I didn't have to jump back and forth between the two in my folder. I've got PLANS for organising that physically though for future participants.

## 8.3. Third Meeting.

This interview, I feel, went much better than our café chat. I felt better prepared for sure, and I think that had to do with me relistening to things beforehand. I needed to come up with those extra questions, so I didn't have to listen to ALL of the recordings, but listening to bits and pieces really did help me come up with some of the new ones.

I was definitely very stressed that day because of personal things, but I was able to put it out of my mind during the interview well enough I think. I'll have to listen back to be sure, but I doubt they could tell. And frankly, it was nice to put it out of my mind for a little while.

Their suggestions for how to improve the study were VERY helpful too, mentioning small tweaks that I hadn't considered and also rationalising things that I had been struggling with, especially the aspect of making sure I'm inviting enough for people to say no.

Overall, I really think this study went well. I'm going to relisten to everything this next week and just make some notes before I try to transcribe the whole thing, but I've got a lot of insights that I didn't have before and I know I have lots of data as well. I'm also more convinced than ever that I don't need to take notes while recording, as they seemed to just detract from my attention. I also really liked having the meetings over meals – people tend to lower their defences over food, though I'm not sure it'd be practical for all meetings and all participants. Might be worth thinking about though.

## 8.4. Barley Hall follow up.

It was really good to get Teagan's view of the changes at Barley Hall. Even though she was not my original participant to Barley Hall, she was perfect for a few reasons: she had visited Barley Hall before the pandemic, but importantly, she has dyslexia (like Alfie) and a joint disorder (like Amanda) and could offer insight into both those aspects.

Her input on the map especially was helpful. I didn't realise that having different contrasts on a map would be a strain, but now that she had mentioned it, it makes complete sense. Not only does it make it more readable to be only dark on light printing, it would also save a small amount of ink on each map (which would add up, given how many maps they have printed), and given their eco-drive, that would be another easy win.

One thing I did notice going around this time was that the staircase that leads to the closed off area was almost hidden. It wasn't obvious that it was an area that was closed off, and that helps with people feeling like they're not missing out.

# 9. Lisa.

## 9.1. First meeting.

- Seemed very anxious any time groups got near
- Slipped through the mum and toddler group quickly
- Quite nervous with me but seemed to relax after I admitted my own anxiety and experiences
- Still seemed more than ready to be done by the end of the pub chat
- Didn't record visit, seemed too nervous
- Quite quick visit too
- Not liking some of these questions – need to reword them

# Appendix F – Interview Design for Organisation.

This appendix contains the questions that I asked staff during my ethnographic observations and interviews.

## 1. General questions.

These are questions that I asked during all observational interviews with front of house staff members.

- What's your favourite thing about your site?
- What's something you would change about your site?
- What's something good about your site in relation to accessibility?
- What's something you would like to see in relation to accessibility at your site?

## 2. Follow-up interviews.

I conducted several follow-up interviews with management staff. The questions were based on my observations, and they are listed here.

### 2.1. Ellen and Issy (Treasurer's House).

#### 2.1.1. General Questions.

- Can you tell me more about your role and responsibilities?
- What's your favourite thing about Treasurer's House?
- Are there any staff members who have asked for disability accommodations? Is there a process for handling these requests? Has anyone gone on long term sick leave? Are there any mental health programmes?

#### 2.1.2. Themes from Participants.

***Personal Interpretation Boards.***

These were **incredibly** popular amongst the participants. This isn't really a question, I just wanted to give this feedback!

***Lighting.***

All participants understood that this was a conservation issue, but there didn't seem to be any attempt at compromise. This was a comment not just amongst the participants but also amongst other visitors and the staff. Is there some way to mitigate this?

***Seating.***

Literally everyone said there weren't enough seats – even those who found the chairs they could sit in them.

- Pop up seats?
- Signs on sittable chairs?

### 2.1.3. Notes from Observations.

*Layout.*

The basic layout of the house is slightly confusing. Obviously, this can't be altered, but are there ways of making it clearer?

*Staff.*

By and large, staff interaction was amazing. Everyone had nothing but glowing praise about the staff and how helpful and comfortable they were with them.
- What kind of training does the staff receive?
- How is the House specific training handled?
- How can Front of House send suggestions/requests/feedback?

*Active vs. Passive Accessibility.*

- Could I get a copy of the style guide?x
- Is accessibility part of early discussions?
- Who is "in charge" of access? Is it managed site by site or is there an area leader?

## 2.2. Mary (Abbey House).

- What are the duties of the duty manager for the day?
- What are the duties of a visitor assistant?
- Who made the decisions for the changes in terms of COVID measures and how were those decisions made (if you're able to answer that)?
- What kind of training do front of house staff receive? I was especially impressed with everyone's dedication to accessibility, and I'm very curious if training has anything to do with it!
- Is there a policy regarding lighting levels that I could read?
- Are there any plans to keep some of the COVID measures, or will things revert back to 'normal' once restrictions have been lifted?
- There were a couple extra staff members I saw throughout the day. One seemed to be some kind of cleaning crew (they were disinfecting things whenever I saw them, but they were also very unobtrusive about it) and one was some kind of technical/maintenance team member. Could you tell me what those roles actually were and what they're duties are?
- There's currently a cap of 36 people in the museum – has this had any kind of impact on admission levels? Ironically, at Barley Hall, having a cap on people in the museum seems to have increased admission rates, but that may be more an impression (there's more a steady flow of people rather than very quiet times and very busy times) than an actual increase.

## 2.3. Maggie (Barley Hall).

- Barley Hall findings
  - Layout – Maps

- Most were slightly confused and worried that they'd missed some sections – even with the new layout, people ask about the buttery/pantry
- Participants specifically suggested maps to mitigate
- Showed maps to a dyslexic participant, who really liked them except the black on white/white on black switch up
- Slight adjustment to steward's room, as sharp turns are quite hard on hips
  - Lighting
    - Inconsistent lighting was difficult
    - Of course, buttery and pantry were just too dark – at least no reading required
    - Lesser chamber table too dark to see the instruments well
  - Thresholds
    - Some kind of rope to grab and help go over the threshold?
  - Seating
    - Fantastic – people felt welcome to sit anywhere and it really helped everyone
- General findings
  - Personal interpretation boards
    - Handheld boards meant that they could be moved around – especially to an area with better lighting
    - More personalized experience – also means you can have multiple strands of interpretation instead of just the big boards
    - One participant specifically suggested a small board in each room explaining what the room would have looked like/been used during the period
  - Active vs Passive accessibility
  - Dictation vs dialogue
  - Embedded accessibility
    - COVID-19 measures

## 2.4. Dr Heather Smith (National Trust).

- Role of duty managers at sites?
- COVID policy?
- Categorisation of properties?
- Impact of COVID on the "for everyone, for ever"?

# Appendix G – Ethnographic Observations.

This appendix contains all the field notes and field diaries from my ethnographic observations at case study sites. Field notes were written during my interviews and observations, noting details and events as they happened. Field diaries were written after meetings with participants to allow me a more reflective and reflexive way of thinking about my interviews and observations. They are arranged alphabetically by site, then chronologically within that group.

## 1. Abbey House.

### 1.1. Field Notes.

- Stephen
    - 21 years here
    - Accessibility of the site
        - Level access
        - Fire exit from upstairs
        - Braille guide, but slightly out of date
        - Street
            - No lighting changes anymore – gone now because of visitor feedback
            - Bringing back sounds
            - "stepping off a bus to the past"
            - Not labelling everything keeps people in the moment
        - Hands on sessions – novelty items especially
- Fave – it's an experience
    - Loved being a Victorian green grocery
    - Loves sending someone away with a smile and the fact that they've learned something
- Remembering – Victorians didn't throw away a lot of things
    - Lots of mending
    - Older people come in and say "I remember seeing something like that in my grandparents' house"
- COVID
    - Limited numbers – 36 total
    - Groups of 6
    - Childhood gallery closed – too narrow
    - No interactive and dressing up (basically all the things that made it child friendly)
    - No samples in the shop for people to pick up and handle
    - Takes away from the experience – takes the magic out of it
- Layout
    - Likes how separated the two levels are
    - Upstairs – penny machines, toys from the 19$^{th}$ century to today
    - Community gallery changes – Patrick Bouen
    - Street is popular
    - Also likes the changing exhibitions

- Change the shop around a bit too, make some thing more obvious to customers
- Changes
  - Craft tables coming back
  - No Santa (he was behind a screen)
    - Relaxed Santa – they come to Santa when they're ready rather than queueing up and taking their turn immediately
  - Miss having people back in frankly
  - Bend over backwards – love being interactive
  - Here to assist visitors
    - Little bit of info without being overloaded
  - Took away notes on the street (touch point)
- Interaction between groups
  - Temple Newsome was horrific – stand-offish
  - More like a family here
  - Good interaction between groups
  - People sharing experiences with each other
- Rich was very helpful and low key
- Got to be chatty to do this job
- Want to be approachable
- Chris chatted with a visually impaired woman for 1.5 hours the day before
- "Visitor assistants"
- REALLY friendly with each other

Chris

- Loves working here
- Very chatty
- Used to have smells – but they kept mixing up the refills

Gilly

- 10 years
- Masks, handwashing, sanitizing stations, one way visitor route, closed childhood galleries, limited numbers
  - New position added – front door person tallies the number of people and also helps people log in using the NHS app
- Layout
  - Low light complaints
  - Listed building – last refurb was 10 years ago
    - Changed the pub window so that everyone upstairs could see it now, not just the people taking the stairs
- Level access, ECVs are a bit too big for the lift
  - But they do their best
  - Had a chap in on an ECV and they were trying every which way to make it fit in the lift, even trying to take the handles off the inside of the lift, but it was still a few centimeters too big
- Lots of people were working from home, which was COVID
- Very cohesive
- "Lovely team of people"
- Fantastic interaction
- Safe place – get on with mates, home away from home
- Pleased to come back to work
- Sharing the history
- Want to put the crafts elsewhere (not the main street) – reposition the places of things
  - Nice to watch the kids work together and have fun and interact

Julie

- Swap places around on a shift if they want

583

- They choose their spots in the morning, it's a very democratic process
- Some prefer one position over another and that's fine
- More staff on the floor because of the tally person
- Busier times, more people – depends on visitor levels
- Lunches at the same time
- Like the cap on the numbers and the booking system – it can get VERY busy and this helps to even it out

## 1.2. Field Diary.

Today was hugely successful. I was only there for the morning due to a personal emergency that happened over lunchtime, but I was able to speak with almost everyone who was working that day. Everyone was really helpful, and it was clear that they all got along well. They were on friendly, familial terms with their coworkers but also with their managers – Steve referred to his managers by their shortened names, indicating that closeness, but also he knew who was supposed to be in that day management-wise. I certainly don't always know that at work, so they clearly communicate very well.

It was REALLY refreshing to see the interaction between front of house staff too. Everyone has been so cut off from each other, it was clear that everyone at Abbey House was really happy to be together again.

I think the term "visitor assistant" is really telling, and it was something that everyone clearly took pride in. I want to see what the other places call each of their positions, as I think that has some implication on how engaged the employee is. There may even be some research on this already, but "visitor assistant" means something different to "visitor experience host" which means something different to "admissions host." This is definitely something to follow up on at the other sites.

I only briefly met Rich, who was the duty manager, but he responded very quickly when he was called on the radio. Everyone did, actually, despite how big and sprawling it is.
I found it REALLY interesting that they said most visitors liked the layout of the museum. That's certainly not the case at Barley or Treasurer's, and they have equally confusing layouts. I didn't see any maps, but the building has also more of a leisurely stroll atmosphere to it than the other sites. More evidence that one size doesn't fit all. However, the fact that they had signs for the one way route also gave the street a much better flow.

I did notice that though the temporary exhibition had changed, the layout was basically the same. They still had the same positioning of signs and objects, they had the same organization of items. I know that there's only so many ways to change an area like that, but I was really struck by the similarities between the new exhibition and the one that my participants visited.

I definitely want a follow up email with Mary to ask her some more technical questions, and also to discuss what my participants have said, but I don't know if that needs to be in person or not.

Despite how short my day was, I got a really good feel for the atmosphere that they have at Abbey House, and it's strikingly different from Treasurer's House.

I'm not sure what their particular roles were, but I saw a couple people who looked more like technical/maintenance team and they were interacting with the same ease as the visitor assistants. One had a cleaning kit and sort of scurried away when visitors approached an area, but in an unobtrusive way. It was almost like she wanted to let the other staff shine and do their roles. The other was hanging posters in various areas for other LM&G sites and exhibitions, and he was quite respectful of the visitors when they were around and stayed back while they interacted with other staff members, waiting for a free moment to ask for something or to access a particular area.

There really wasn't a lot of people at the museum today, I think I saw 8 other people during the morning, and never in groups of more than 2. It did have a really nice, relaxed atmosphere, and I wonder if the cap on numbers would help Lisa feel more at ease. It's almost forced 'quiet hours' onto the site for all the time, and I really wonder if that's good for access. I know it's difficult financially, but I do wonder if visitors appreciate it, or if they'd rather have the bustle.

## 1.3. Meeting with Mary.

Personal interpretation boards
• Layout
◦ Looking at getting a map produced – on the cards for a while
◦ Led by the access committee
• Lighting – used to change on the Victorian street
• Changes post-COVID?
◦ Kept hand sanitizer, encouraging mask wearing, encouraging social distancing
▪ Reinforced through signage "personal space is lovely, please be mindful"
▪ Very variable in following these
▪ Staff members wear masks when moving around the museum or if public facing
◦ Sneeze screens are still at the tills
◦ Signage encouraging to use hand sanitizer
◦ Staff are taking regular lateral flow tests
◦ Lifted cap on numbers – tickets available online – trying to avoid everyone arriving right at 10
◦ Able to reopen childhood gallery and community gallery
◦ Crafts are still bumper craft packs (probs staying that way)
◦ Starting to think about Christmas
▪ Book room was Santa's Grotto – carry on doing that?
◦ Online engagement has been fantastic – keeping that up
◦ Still have QR code, still will take details is desired
◦ All office staff were "taking turns" to go in and were working from home where possible – LCC policy – now it's easing everyone back in
▪ Working from home will continue but in a more hybrid capacity – green impact as well

- **What are the duties of the duty manager for the day?** Basically the duty manager is there to make sure things run smoothly. They ensure we have enough staff, make sure everyone knows what's happening that day and at what time, that the building is safe to open to the public and be on hand to provide any support needed and deal with any issues that arise. If there was an emergency they would coordinate whatever actions were necessary. They are also there to supervise any contractors on site and ensure the security of the building and collections.
- **What kind of training do front of house staff receive?** I was especially impressed with everyone's dedication to accessibility, and I'm very curious if training has anything to do with it! The VA's training starts with their induction which covers familiarisation with the building, collections, different staff members and roles, emergency procedures, cleaning, health and safety, customer care, cash handling, EPOS training security and daily procedures of all kinds. They have training on facilities available for those with additional needs such as touch tours on demand, ear defenders, torches, magnifiers and wheelchairs available to borrow, braille signage in the museum, all signage is large print, that we will adapt workshops and tours, BSL interpreters available (with advance notice), info on our monthly sensory play sessions and relaxed activities. The more specialised training they receive are things like annual safeguarding training. As one of the few council buildings in an urban area we are a designated safe space and sometimes have to deal with difficult and sensitive situations. We are just trying to organise a refresher of Safe Space training. They have also received Makaton and Dementia Friendly training.
- **Are there any plans to keep some of the COVID measures, or will things revert back to 'normal' once restrictions have been lifted?** This is something we are working on at the moment as a service. We do foresee keeping some of the measures in place whilst others will be relaxed.
- One accessible suggestion that came from the front of house team was for Relaxed Santa. They suggested we turn off the noisy hand dryers in the toilets and replace with hand towels for the day to avoid triggers for visitors who are noise sensitive. We've continued to do this for any event that is aimed at visitors with additional needs.

# 2. Barley Hall.

## 2.1. Field Notes.

- Paul T
    - Not many shifts at BH before COVID
    - Layout
        - Sometimes miss the parlour
        - Sad no buttery or pantry, but it's understandable
        - Confusion at first (thinking they missed the little room across from the Great Hall)

- ▪ Could be clearer on the location?
- Pretty much all take a map or two per group
- No more hands on elements – VERY different experience now
- Wandmaking used to be communal and encouraged interaction between groups
- Interactive experience was a selling point
- Not as many international visitors
- Half term was pretty solid bookings
- Review
  - ▪ New layout "could stay"
  - ▪ Open up buttery/pantry
  - ▪ Still use the maps
  - ▪ Better signage
  - ▪ Early sign posting of the toilets
  - ▪ Less strict on the one-way
  - ▪ Bring back interaction – more sensory
- Like that it isn't overcrowded, it maintains an atmosphere
  - ▪ It's a *home* when it's not packed

Jessica

- Before
  - ▪ It's bigger than people expected
  - ▪ Visitors never really knew what to expect
  - ▪ Lots of walk-ins
    - ▪ Still saw PLENTY of walk-ins while I was chatting with her for ~30 minutes
  - No pre-bookings
  - Never been super accessible – but at least we're open about it
    - ▪ Did whatever we could to balance that out (free admission if can't go fully around the site, ie in a wheelchair)
- Changed
  - Atmosphere – used to be more spontaneous
    - ▪ Now it's more clinical and regimented
    - ▪ Less *chatting* with visitors, as there's just so much to tell them regarding COVID measures
    - ▪ Also the sun hits the screen and makes it hard for staff and visitors to see each other
- Now
  - Still positive feedback
  - Building and exhibition are popular
  - Small children – vastly different experience
    - ▪ Must be on time
    - ▪ Less interactive
    - ▪ Take home wand
    - ▪ Less to DO – leads to shorter visits
- No response to maps
  - Simple instructions aren't simple instructions to a lot of people (i.e. use the toilet before you go upstairs)
  - Reuse the maps – put them back into circulation after a quarantine period, environmentally conscious
- Not as much grumbling over buttery/pantry as expected
- Would like the shop & admissions back together – so little to do when it's separate, it's very boring now
  - Liked seeing the customers come back out – less engagement with them now
  - Feels more detached from visitors

- Weirdly more interaction with fellow staff members – but only kinda
  - They really only pass each other a few times during the day, there's not much chance to chat
- Management really receptive to suggestions – if there's capacity
  - Subtitles
- Far stricter on COVID enforcement, making them feel safer
  - Overly cautious, if anything
  - Screens reflect a lot actually, especially at certain times of day
- Wheelchair access – free admission since they can only access the ground level, and even then, from a different entrance
  - Portable ramp
- Fave – very unique – more interesting than most people expect
- Really good relationship with management – trust in your responsibility/work ethic so you're not being micromanaged

Interaction still very personable (same with Paul)
QUITE a long intro though
Finn and Paul R both dropped in while I was there
- Chatted with each FOH and asked after them
  - Finn on duty, also cleaning
  - Paul off rota, still checking in on them

## 2.2. Field Diary.

It was really interesting to get two vastly different perspectives on Barley Hall. Jessica primarily works at BH, while Paul was primarily at one of the Walls sites that has since closed because of COVID. Despite their disparity in how long they've worked there, they still had similar views of how things changed, especially with the interactive element of the site. That's something that it has in common with Abbey House, that taking away the interactive elements has made it less child-friendly and really changed the experience. I wonder if the same will hold true for Treasurer's House, since that wasn't nearly as interactive (at least, in terms of multi-sensory activities) before COVID. Not to mention the impact on accessibility, which was felt by the whole staff.

The interaction between the different groups was exactly what I've come to expect from YAT. Everyone is very personable with each other, on very good terms, and even if they don't know each other very well, there is an element of comradery amongst everyone. While I was there, one of the cleaners came by (he normally works as a Viking interactive at JORVIK, but has joined the cleaning team and goes between the three sites, cleaning high contact areas throughout the day) and was chatting and laughing with Jessica, even though he'd never worked at Barley Hall before and therefore didn't know her very well.

The same held true when it came to management. Both managers (one on duty, one off rota, so he wasn't in charge of the building) came down multiple times in the span of about an hour and checked on the staff members. They asked how they were doing and also how the building was doing, a quick way to ask if there was any situation they needed to be aware of or deal with. It was quite a small interaction, but it was clear that there was a good rapport between the managers and the front of house.

It was really interesting to see Finn especially, as he came down with a bucket of disinfecting wipes. He didn't leave all the cleaning to the front of house staff, he dug in beside them to keep the site clean. It was nice to see that the managers aren't "above" certain types of jobs, especially the less glamorous ones.

## 2.3. Meeting with Maggie.

- Planning on keeping the layout now, and the maps, thanks to feedback
  - Visitors and staff
  - Also this research
- Buttery and pantry have been an ongoing issue
- Noted the design change per Teagan
- BH actually used to have handheld panels – changed with the redesign
- Will talk to Sarah about adding the panels to travelling exhibitions too
- Wondered if any participants would check out the website to see how accessible it really is?

# 3. Treasurer's House.

## 3.1. Field Notes.

*Sunday 8th December.*

- Sarah and Anne on reception
- iPad – PP on rooms
  - Fonts change a lot and are kinda terrible
- Audio tour no more – 10 years gone
- "Old fashioned" book guide – all photos, no text
- Scanner for NT cards
- Gnome trail – for everyone?
- 14 steps down to cellar
- Strollers to cupboard (volunteer breakroom)
- Space heaters and radiators
- Knew # of steps off top of the head – handrail
- Had someone look around to make sure someone (walking stick & mobility problems) could get to the café
  - Handrail continuously down
- Touch tour – copies to take around (3-4)
- Language guides
  - German
  - French
  - Italian
  - Spanish
  - Dutch
  - No English – same as guidebook?
- Trail is year round
- Want to have Chinese guide
- Poorly translated guide complaint
- Dec 22 – April 1 closed
- Tag system for bags as well
- Heavy door but swings fairly easily
- Did have someone bright stuff up to pay
- "Quirky"
- Count people who come back through reception to café?
- Tags behind door and till
- "Steep" stairs
  - 2 people grabbing handrail hard in a span of 30 seconds

- Showed which chairs to sit on – lady with a stick
- "Volunteers to chat with"
- Chair is by door which opens and closes a lot
- "Handrail on the left goes all the way down"
- Don't question if "disabled"
  - Half off
  - WC users are free
  - Companion free
  - At discretion of reception staff
- Braille guide
- No special disability training
- Things (touch tour, braille guide) not asked for often
- Normally get halfway through and then need to sit
- Garland moment
- Always 2 on admissions
  - One behind desk
  - One beside
- Hand dryers
- Turn taps (not levers)
- Offered to store WC, explained chairs in each room

## Monday 16th December.

- No OAP/concession tickets
- "Because that's not precious"
- Luggage tag
- Hannah and Issy
- New touch tour – large print!
  - Brought people around to trial it – different levels of visual impairment
- Water bottle on desk
- Did manage to bring stuff up from shop for till
- Gent with crutches – no extra info (still explained the stairs)
- Volunteer with LD (Downs?)
- Some are unemployed during closure, some are on contract
- Membership training
- Year in review training
- Cluster: this, Goddards, Beningbrough
- One confused group (2 people)
- Lots of confusion on layout
  - Especially those who don't listen to instructions
    - But is it?
  - Go up about halfway through 2nd floor staircase, then turn around (Blue Flat area is very confusing?)
- Guides are meant to tell them about the flow – in GH with 2nd staircase
- 2 people asking how to exit
- Super echoey in reception
  - Slightly difficult to hear
- Gent with crutches made it around
  - Staff moved out of doorway to give room for him to get through
- Almost everyone has a second job
- Confused couple went from admissions to kitchen in search of café

## Tuesday 17th December.

- Ben and Hannah

- Things I missed on Monday:
  - Guide dog (full hearing aids)
  - Downs syndrome
  - Learning disability – got lost and helped them find the rest of their party
- Nice and chatty
- NT photographer coming around – finally saw manager
- Devon and volunteers did the decorations
- Some volunteers have been here 30 years
- Ran to open the door for someone
- Helped take buggy downstairs
- Alarms on necklace
- Door does not swing closed automatically
- 1 lost
- 1 couple turned around
- Venn diagram of dept. Responsibilities
- Shop till is only till the café has access to – couple volunteers are trailed on that till to do both
  - Café isn't SUPPOSED to do shop stuff but they do when they need to
- No dogs in the house
- SO many volunteers – FoH don't always recognise them
- 13 rooms – 10-15 volunteers a day (5 youths on the team, everyone else is retired)
- Admissions – back up for the ghost tours
- Regular ghost/attic tour guides are hired specifically for that
- DM – briefs volunteers, deals with emergencies, basically "on call"
- 17 volunteers on Tuesday! Normally
- Boards are quite popular
- Training
  - GDPR
  - Accessibility – ?
  - Membership
  - Regional training
  - Fire
  - Management
  - Inspire to Engage
- Mystery visits are about membership
- Less necessary engagement because of layout (first volunteer is the intro to the house)
- Garland WAS about access – steward noticed someone struggling to get up and adjusted it – no complaints that were known about
- Longest stretch was about 5 minutes without a visitor at reception
- Similar sitting chairs across properties
- Takes a long time to get new things – lamp on desk took a long time (how long?)
- Suggested folding chairs to take around
  - Store them by desk? In info stands?

## Wednesday 18th December.

- Ben and Issy
- Wow rush at opening
- Liz
  - Yes on confusing layout
  - Sitting a decent amount
  - Tablet – scroll through – more coming in the next year ("I'll believe that when I see it" according to another volunteer)
  - 20-25% use the boards

- o Wants it to be warmer, lighter – MUST be some balance between conservation and actually being able to see
- GH – explained panels, colouring of them
  - o People sitting in chairs (both had sticks)
- Queen's room – not often sitting
- Christine
  - o Don't really need to sit
  - o 20% board use
  - o iPads to each room coming
  - o Doesn't want anything to change (in general, not specifically regarding accessibility)
- BDR
  - o Sit quite a lot
  - o Boards get used more during busy periods
    - ▪ Ask guides to explain/expound on something
  - o French translation is terrible, want a better quality
- Paul
  - o GH – points out the chairs
  - o All about gauging visitors as they walk in
    - ▪ If they go straight to the boards, they don't want to talk
    - ▪ If they struggle going up the steps, offer the chairs
  - o Goal is to make the visit pleasant
  - o He's also Father Christmas
  - o His aim is to make them have a good visit, a good time
  - o If he could change anything, he'd adapt the old toilets in the foyers to be accessible toilets (there's none on the ground floor)
  - o He's also the Friday day leader
  - o Been here 5 years
- Training
  - o Customer service
  - o Membership sales
  - o In-house training
    - ▪ House specific
    - ▪ Fire training
    - ▪ Ramps, accessibility
    - ▪ Bags, wheelchairs, pushchairs
  - o GDPR
  - o How to deal with terrible people
- Issy – wants the place warmer
- Ben – more signposting, better heating, better lighting levels
  - o Could also do more for colourblindness – contrast? Still have to follow design guidelines
- DM – open/close building, "on call"
- Don't print on stark white paper anymore – light green or yellow
  - o And yet, the desk stuff is on white paper – concern more for visitors than staff?

*Friday 20th December.*

- Great Hall Observation (1143-1213)
  - o Total: 24
  - o Boards: 2 people
    - ▪ They used 2 of the boards each, stood near the info stand to read them, looked around the Hall in response to reading things
  - o Seat: 0

- - o Layout confusion: 7 (3 came back from King's Room confused about where to go)
    - o Really engaged with visitors – not many really lingered but those that did spent quite a lot of time here
  - 6-7 people in the Minstrel's Gallery is completely too many – choke point, and yet there's written interpretation here
  - Christine
    - o 3rd year
    - o Socialise out of hours as a team
    - o Favourite thing is the story of the House – such a uniqueness to the site, it's about one guy
    - o Everyone is so welcoming
    - o Wants more things for children, more exhibitions
  - Volunteers are really close and sociable
    - o Little bit cliquey
  - Send an email to Natalie, Anne, and Trish about coming back in April and also about scheduling meetings with them during closure
  - Better pricing sign in the foyer
  - No disabled toilet for men – only in the women's, separated from the ACTUAL women's toilet but it still makes men uneasy
  - Audio guide was Frank Green talking about the house
  - Used to have a lift
  - David – cluster manager

## Tuesday 13th July 2021 – guided tour

- People gather outside
- Slight confusion over where to stay until your starts
- Guide takes you down to the toilet – waits a decent amount away so no pressure for speed
- REALLY weird to see it so empty inside downstairs
- First room is an overview of the history of the site
- Romans up to Frank Green
- Room 2 – mention the sittable chairs in each room
- 5 people per group, so six total with tour guide
- Groups do cross each other a bit – in great Hall and bottom of William and Mary stair case
- It's a lecture tour now, so less interaction
- Well less spontaneous interaction
- Little bit of chit chat but there's not the extended kind I saw before
- Crossover at the top 9f the stairs too
- VERY similar script from what I've heard of the other tours
- Mild disappointment from the guide about the clocks not working – especially since 2 are quite important to the tour
- No stopping in the King's room because covid??
- But the minstrels gallery, which is smaller, is okay
- No stopping in the gallery room too
- Finish up with a slide show at the end – chance for everyone to sit
- Slide is is stuff from the previous three rooms (minstrels, Kings, gallery) that we couldn't stop and look at
- So now we can sit and listen to the lecture as we look at the pics
- Good close up pics – might not have been able to see these details on a regular tour
- However there is very little circulation in here, so it's slightly stuffy and I kinda just want to fall asleep

## 3.2. Field Diaries.

- Anne and Sarah – very lovely, very helpful
- Not much official disability training – but very eager to help
    - Accommodating
- Take notes with phone? Insert photos
- Knew the access off well – especially how people can get around (# of stairs to café)
    - How to determine who needs the information?
- A lot of good intentions – super hard to read the PP room guide and no text on the room book
    - Need to redo both
- No audio guides but still have references to it
    - Thorough exam of the site to make sure everything is up to date
- Take photos of toilets to demonstrate equipment
- Really want a pull gauge to measure how heavy the doors are
    - Any lit on how heavy is too heavy?
    - Volunteers know about the heavy door, but admissions don't
    - Who to talk to about this?
- BDR lighting is very divisive, even amongst the staff
- Advertise discount admissions?
- Totally forgot to introduce the research – really need to do that, probably coloured some of the early discussions
- Seemed a lot of people were a bit lost
- What does staff do during closure?
- Disability policy for staff? Anyone on extended sick leave? Mental health programs?
- Genuinely pleasant people
    - Bit of a disconnect between FoH and Management
        - Changes to Father Christmas bookings, seemed to be frustrated by the limitation
- Sarah – dyslexia
- Any staff accommodation?
- Doing what they can with what they have
- Frank Green said not to change a thing – how seriously will they take this?
- Definitely a line between admissions and room guides
    - Def need to observe room guides
- The access offers are there, but no one's using them
    - Active vs passive
    - Advertise?
    - List on admissions?
- Hearing loop – always on?
- Traffic light system?

- Unintentional obliviousness is a huge thing
- Confusing layout – the admissions people say it's because people don't listen, but that can't be all of it
    - ADHD
    - Dyslexia
    - Audio processing issues
    - Memory
- New touch tour – better printing, much better interpretation

594

- o But will it be used?
- They have membership training, why not disability training?
- Need to set up a meeting with Trish and Anne – any longer term disability? Any accommodations? Any disabilities on the team?
- Genuinely pleasant people and also eager to help – but super need disability awareness training
  - o Very common comment: staff were brilliant (let's just make them a little more brilliant)

*Tuesday 17th December.*

- Conflicting info about training – ask higher up?
- Very compartmentalised
  - o Admissions and retail
  - o Café
  - o Volunteers
- What do the managers do?
  - o No toilet check sheet
  - o No hourly walk around
- People don't sit a lot – same red chairs across the Trust
  - o Maybe pop up stools?
- Banister WAS about accessibility – no complaints, one of the volunteers saw someone struggling and changed/adjusted it
- Some volunteers have been at TH for 30 years – THAT is buy-in
  - o How do they incentivise this? Why are people staying?
- Alarms around neck – good way to call for help in a sprawling place like this
- FoH is very eager to help – down to engagement training
- SO many volunteers omg – they really engage with the visitors
- Tour guides are only around for the tours- what kind of buy in do they have?
- As always, it takes time to get new things in – apparently, it took forever to get a lamp on the desk (for lighting levels?)
- I think the info stands in each room are a missed opportunity – floor plan? Pop up stool? Reading lamp?
- Tomorrow will be good for volunteers – but chatting with each over lunch is good (one on one chatting is helpful)
  - o Catch the volunteers on their break?
- Also really need to have a proper, full day with them – but that's for spring
- Feel very rushed with a lot of this – partly the time of year
  - o AH – March – take that month off (or go down to fewer days a week)
  - o BH – April – stretch it out more/use DM shifts?
  - o TH part 2 – May
- Also, make weekly write up of themes

*Wednesday 18th December.*

- The volunteers are SO passionate about the House
  - o Need to ask them how many years volunteering
- Really want to check their training
- Asking one thing they'd change is a really helpful question – also ask them their favourite thing about the House
- Interesting how varied some of the responses are – how often people sit, how often they use the boards
- It seems the more comfortable the volunteer is with people, the more aware they are of disabilities – is there a link?

- - Someone mentioned that they link it to their own need to sit/rest, backache, whatever
- Paul and BDR person were both really in turn with body language – is that with training or experience?
  - Helpful with disabled people
- Again, everyone is really lovely but seemingly isolated
  - Do they hang out after work? Have parties?
- Need to ask about lighting
  - One volunteer mentioned the lighting and WOW does reception get dark – meter reading in morning and afternoon
  - Need to be more systematic in taking readings
- BARELY saw management
  - Super division between them
- Don't always recognise the volunteers
- Methodology for taking meter readings
- Ben seems quite up on access stuff – but he's also one of the more enthusiastic and personable of the reception staff
- Some kind of chart for the terms? Venn diagram of responsibility
  - More like isolated spheres of interaction
- How does management put together House training?
  - Specifically "tips and tricks" – what is the communication line?
- iPad roll out?
- If FoH has suggestions/requests, what are the mechanisms?
- Observe from the minstrel's gallery for 30 mins
- Actually DO the touch tour
  - It's for Visually Impaired visitors…. In text format
- Paul was a great room guide – want to talk more with him
- Need to get the design guidelines

*Friday 20th December.*

- Need to chat more with Mike (? bald guy with elf ears)
  - Knew a great deal about The that I hadn't heard yet
- Day leaders are going to be REALLY helpful
  - Volunteers with an extra level of passion
- Ben was unsure I knew Avril – reflection of culture of isolation in TH?
- Need to organise my days better (sticking with reception, watching rooms, chatting with volunteers, rather than all in one day)
- Overall, it's proven just how useful this kind of research is – there's so many behind the scenes things that are preventing change
- Can they even trust management to listen?
- Need to be more systematic about my questions too – catch them in the break room?
- Room observations are great too – need to structure those a bit more
- Sarah – dyslexia, but mild – doesn't need many accommodations
  - She has a hard time reading on stark white paper – so why are the sheets on the desk stark white? They don't use white paper for visitor sheets, why reception sheets?
- SUCH variation in lighting levels – need to make a map/diagram of the levels?

## 3.3. Meeting with Heather.

- Role of duty managers at sites
  - Different way of operating than AH/BH
  - Redoing what it is anyway
  - Rotates betweens head of department

- o Don't do anything unless they're called
- o Don't practically need to do anything
- o Heather WOULD, though, just to check in
- o Most of the time, they just cover breaks at most
- o In COVID times, they've been responsible for more cleaning tasks and floating around
- o If they're not called, they don't need to be around – not entirely a bad thing
- o But still no toilet checks so
- o More of a Treasurer's thing than a National Trust thing
- o Rethinking the role – someone wanted a more active role for DMs, much more of a service model than waiting to be called
- o Changing the name as well – more of an emphasis on service
- o Proposed way forward – Heather will come back about this
- o Higher visibility and proactivity
- o Not always the head of department doing this, maybe someone else?
- o How much has this change been discussed with Front of House staff? Heather to follow up on consultation process
- o Organigram just doesn't exist for the lower down, property level – follow up with Heather
- COVID policy
  - o Daily briefing for months that went to all staff; then it became 3 times a week; now it's twice a week
    - ▪ M – Stuff you need to know (what Boris means)
    - ▪ F – Nice to know (fun things that have happened at properties)
    - ▪ Always an intro from an executive
  - Weekly video blog from Hilary McGrady
    - ▪ Transcribed nearly from the beginning (missed first 2 weeks)
    - ▪ Added subtitles
    - ▪ Just audio version
    - ▪ Transcribed in Welsh
    - ▪ Sometimes a walk and talk – but people are finding that distracting (neurodivergent)
    - ▪ Even on her holidays, she's had someone else do it so that there's always a video blog each Friday
  - Lots of text-based things (the blog has been a good way to diverse)
  - Lots of links to Acorn system – policies and procedures
  - Webinars throughout last June as they prepared to reopen
    - ▪ Sessions with experts and heads of departments
    - ▪ Regionally as well
    - ▪ Every week for a while, less often now
    - ▪ "How to help you make sense of all the words"
    - ▪ Listening in sessions – general feedback
    - ▪ All recorded, all subtitled
    - ▪ Lots of social media for external consumption
  - Even on furlough, you could keep up to date (if you wanted)
  - Wellbeing webchats – 2 a week for several weeks, now about once a fortnight
    - ▪ People are busy at work now

- - Furloughed staff were a different group than those still working, as they were having very different experiences
- On-property briefing as they came back to work
- Mandatory e-learning courses
  - Re opening safely
  - Staying safe (many visitors were being awful when we re-opened)
- Continuity group met every morning
  - Meet every day as a way of keeping things consistent
  - Changed from "how are we going to deal with all this" to "right, we're doing this, so how are we going to go forward"
- Really DID try to pivot
  - Set up all these things quickly
  - Didn't really repeat things or change the method of delivery
  - Didn't do a lot of direct checking in with various teams (left that to more of a regional team)
    - Unsure how successful that was
- Heather checking in who is now in charge of Treasurer's
- "Implications of all the info coming out of all the other groups" group
  - Still needed all these other bits that are normal for every year – like a member's handbook
  - New signage that was consistent
  - How does access development factor into this
  - More regional discussion feeding into this, which would then go upwards
- Cascading information didn't always trickle down to the front of house
  - But then, it would be overwhelming for a lot of people
- Daily briefing was great but after several months, it was hard to keep up
  - Good for consistency
  - But it also felt like if you missed a couple days, you wouldn't be missing much – except that you could miss something crucial
  - Seems like the two a week worked best
- Lots more people than usual contributed to these discussions
  - Especially volunteers – higher risk of COVID in that age tbh
  - Lots of emotional responses – mental health impact?
  - Got about 2/3 of volunteers back, but not sure if the last 1/3 back will be back
  - All staff back
  - Basically all houses back open – some are open for fewer days a week (TH is 4, I think?) – fewer staff to open the properties

Categorisation of properties?
- Think about interpretation of how we open
- "Treasure Houses" – larger houses, more significant collection, ex: Beningborough House, mostly London and Midlands and Southwest (where most of the houses are) – more support than other properties, not necessarily more funding, more priorotised
- "Small properties" – only opening infrequently, tour-led, minimal free flow, low staff, building is more important than the contents, part of a larger portfolio, better utilised by the community or a live-in family, may need a different volunteer structure
  - ~60 properties

598

- Used to be 'little gems' but people found that upsetting??
- TH is here
  - Important because of its location in York, but not really important in and of itself
  - More liberty in terms of interaction with visitors
- Setting up a new approach to working with disabled audiences
  - Especially training
  - Dementia, autism, sight/visual awareness, deaf awareness/sign language
  - Pilot properties to try out this training
  - Half are "help us shape this training" and half are "here's this training, tell us what you think and we'll adjust"
  - Training in how to give a tour
    - Sometimes a separate tour, sometimes just inclusive in the general tour
  - Touch tours development/training
  - Focusing at little gem sites because they might be feeling overwhelmed with everything else
- Funding bid for more face to face training (arts council)
  - And the build up resources
  - How to develop a touch tour
  - How to audio describe
  - Looking to external consultants and partnerships

Impact of COVID on the "for everyone, for ever"
- Everyone Welcome program – test programs
  - Action based research wasn't going to be a thing thanks to COVID, had to adjust
  - Forced to re-evaluate whether that was the right method anyway
  - How do we set this up correctly now? That was Heather's focus in adapting this program
  - Doing things on test properties wasn't going to be viable
  - Working groups and external consultants/partnerships was the way forward
    - Day to day interactions feed into this via the working groups
- Inclusive Leadership
  - Not just 'leaders' – everyone is a leader in a way
  - How do we incorporate that information? Recruitment?
    - Declaring identities if they wish to
    - Confidence in the organisation?
  - Preparing staff to interview a variety of candidates (one size does not fit all when it comes to interviewing)
    - Putting enough knowledge in the people/HR department
    - Sign language example
- Cultural change of the organisation
  - New inclusion leader (from corporate and university)
  - Leading them through the other objectives
- Access stayed through all these changes
  - Heather leading on this with the new inclusion lead
  - Picking up some of the stuff from the earlier work
  - National and local partnerships (RNIB, for example)

- It's not just about some tick-box programs, it's trying to changing the approach
  - Not just having a dementia café, it's about noise levels and calming areas and pathways and things like that
- We're welcoming people with all their experiences, all their talents, and that includes staff as well as visitors
- Welcome vs belong is something different
- Training, access audits, access standards (drawn from various sources including comments from disabled visitors)
  - Standards – partner document to other areas' standards (like food and beverage)
    - Correct distance between tables for wheelchair users, dampening fabrics, etc.
  - And obviously, lots of crossover between areas and documents, but it's an evolving thing
  - Reasonable adjustment process
    - Goes trhough the people team rather than just Heather
    - Originally going to launch in October, might be this summer
    - Ways to fund quickly and easily and get people working the way that they work best
    - External partnerships with suppliers
- Separate stuff for outdoors but not super relevant to me
- Working with RCMG (?) around disability heritage
- Heather is getting several millions of pounds to help with the delivery of the access standards (bronze level)
  - Want them to level up
  - Properties then bid to level up even more
- Inclusive histories
  - Driven by BLM movement but then stepped back and said "we need to be doing this anyway"
- Building back to nearly the pre-pandemic levels of membership, which is fantastic
  - Lots of people are coming to join for their cause rather than the financial benefit
  - Really interested in how many disabled people will join once access increases
  - Neurodiversity is SO MUCH MORE THAN JUST AUTISM
- Playing our Part document is still relevant – grab that from the website
- Two main themes: environmental impact and inclusivity
  - Significance of heritage as a whole in the UK
- Lots of stuff coming out about the whole impact of COVID on disability – and more likely to come out over the next 2 weeks
  - Seems like disabled families especially are shrinking back as everything 'gets back to normal'

## 3.4. Meeting with Ellen and Issy.

- Senior Visitor Experience Officer
  - Behind the scenes
  - Duty manager

- In charge of tour guide, retail workers, group visits, reception staff
- DM duties – open the house, volunteer briefing, reception briefing, first aid, handle emergencies, close house, lock up, set alarms
- Favourite thing: garden – little treasure in the city centre
- Weird little space – unique experience
- Disability accommodation:
  - One tour guide had hip problems
    - About capability – they come to the manager, conversation with HR
    - Reduction of number of tours per day, number of days per week
    - Ask what they can manage
    - Check in with them too
    - Interviews for return to work
    - Conversational negotiation
- Interpretation IS available online – collections website
- First volunteer is to give intro to the boards
- Lighting – conservation AND ecological issues
  - Swap to (brighter) LED bulbs in spring
  - Limit light hours as part of Trust policy
- Seating
  - Want to keep with the aesthetic – don't want to change TOO much
  - Pop up seats coming
    - Tour guide will carry them around on the tour and just subtly pop them up
  - Need to communicate more about the seating with the staff and volunteers
- Adult map coming – leaflet
- Training
  - Reception
    - Membership
    - In house
      - Customer service
      - Operations
    - Spring briefings
      - Staff and volunteers
  - Volunteers
    - Customer service
    - Values and behaviours
      - Good to have it written down
      - Not really CHANGING their behaviours, just reinforcing them
      - They're already doing just fine, but it's good to have back up
    - Trust wide – working on improvement
    - Catch up chat in the morning
    - Getting more standardised and more property-focused
  - Staff AND volunteers – survey at the end of year (anonymous)
- Feedback – speak to the DM – hopefully they feel comfortable enough to come to them with problems
- Day leader meetings monthly – cascade information and news down to their teams
- Tablets are coming out
  - One per room
  - All the collection info
  - Item info
  - "For further info" citations
- Style guide from Heather? Brand guidelines
  - Matte lamination
  - Tone/voice
  - Image library

601

- o NT photographs
- In charge of social media
- Lots of freedom to make your own thing – more relatable tone on social media
- Maria Gavin – regional health and safety + accessibility
- Anne is in charge of accessibility at the House ultimately
  - o Trying to make quick, easy changes
- Thick handled cutlery
- Blue Drawing Room – part of a "vignette" so the darkness was okay and part of the effect/aesthetic
- They're trained to make assumptions about visitors but not *judgemental* assumptions
- Don't have to ask for tablets or maps
- Touch trail – they offer it, but they don't want too many people to touch things
- Can't have too much on the desk – too cluttered
- Really in depth access guide
- Hearing loops – on reception till and shop till
- Would like to include access to the café that doesn't involve steps (outside door?)
- Really trying to go with passive in some instances – but still a reliance on verbal transmission of info (seating, intro to boards)
- Ask Anne about responsibility of reception vs café vs volunteers
- Interesting dichotomy – moving some of the info (layout, item info) to passive, but still relying on active conveyance for other info (seating, intro to the boards)
- Is there a difference in quality during busy vs non-busy days? (they have more time to explain things to visitors?)
  - o How to mitigate during busy times?
  - o On the other hand, do they want to automate everything?
- How are they deciding what to prioritise?
- Feedback from visitors?
- Cycle Issy mentioned: super excited, new tools -> settling in, working out problems -> new issues arise -> frustration and annoyance (spring -> winter)
  - o Similar cycle in other sites?

## 3.5. Meeting with Trish.

- New value guidelines – 125th anniversary
- My volunteer website
- New advertising – 4 core values
- Forever, for everyone -> for everyone forever
- Key values:
  - o We love people and places
  - o We welcome everyone
  - o We think now and forever
  - o We make it happen
- Always wanting to do the best possible thing they can
- How can we respond to more groups of people
- Bringing in sunflower lanyard scheme
- Hidden disabilities are actually written into the inclusivity policy
  - o Just don't know what to do about these kinds of disabilities
- Favourite thing: coming in every week, not knowing who you'll meet – but making it the best experience for the individual
  - o Tailored to the needs of the visitor
- Roles and responsibilities
  - o Deputy team leaver
    - ▪ Helps the volunteers feel comfortable
    - ▪ On call for support
  - o Tour guide support

- - - Didn't like it because it couldn't be tailored
    - Mobility is tough
  - History research group
    - Room to add to interpretation
    - Website is a training tool (HRG)
    - Treasurer's Tales booklets – biographies
- Front of House reapply every season – rehiring is not guaranteed
  - Understaffed – all on part time contracts
  - Gateway job, not a career path
  - Not secure
  - Very front line
  - Short hours per shift
  - High changeover
  - Few opportunities for advancement
  - Definitely financial constraints too
- Love the stories of the collections (not necessarily Frank Green)
- "How the centuries speak to us" through the pieces
- Love the familiarity she has with the collection
- Looking for younger volunteers – want to be more diverse in general
  - <u>We welcome everyone</u>
  - Optics to reinforce the message
- Feedback process
  - Mobility issues – team leader/team relationship is crucial – maybe it's as simple as keeping them in downstairs rooms
  - Stress/hidden disability – encouragement, time off
  - Handled within the team
  - Wheelchair user/speech problem volunteer – worked on the research team
    - Sometimes met at Ask Italian, sometimes in the dining room when the house was closed (opened that door up so he could get in)
    - Hugely beneficial to him and his confidence
  - Team leader -> team leader meeting (with David – GM of the area)
  - Shift briefing – info but also a chance to ask questions
  - Spring pre-season meeting – 203 hours
  - Staff are available at all times – went directly to Anne about something and she followed it up
    - Guardian ad – Octavia Hill quote
- Ramps – best ramps they could get at the time – time for a review though?
- No specific process for handling accommodations – informal, relies on work with team leader and team
- Natalie and Devan are in charge of volunteer training
  - My Volunteering website
  - 27 page induction PDF
  - HRG website
  - Experience, shadowing, talking to the team leader
- iPads
  - Easily editable
  - Zoom in on text
  - Text to speech option?
  - Individualise the settings?
- What would you like to change?
  - Would like to bring the place to life
  - More varied interpretation
  - Costumed guides
  - Music
  - More sensory experience

- o Experiential – like the Blue Drawing Room during Christmas, but over the whole house
- o Music in the Great Hall – concerts?
- o Long ramps – need to be long for the gradient, but could there be other solutions?
- o Classes – tied into the collections (needlepoint, etching, woodwork, etc) – practical, experiential
- o Small lectures on particular items
- o Specific person to head access and communication between groups
  - ▪ Team potentially, but certainly a liaison between everyone
  - ▪ Community outreach?
- o Training is ongoing – this needs to be a thing that is built into the expectations of the volunteers – refresher sessions
- o Lighting. Always lighting.
- o Reaching out to "everyone"
- Touch trail has been reduced in scope
  - o 3D prints?
  - o Samples of textures

# Appendix H: Disabled Participants' Response.

In this appendix, I include my disabled participants' response to how they wish to be addressed within the text. First, I include my email to them, then their responses. I have listed them alphabetically, and removed one participant's full name that he included in his email.

## 1.1. My email to participants.

Hello again!!

A few weeks ago, I had my PhD viva - I have some corrections to make.

First of all, I want to thank you SO much for your time and insight, I genuinely appreciate it and could not have done it without you.

Secondly, one of the corrections that my viva team suggested was to anonymise everyone, as they were concerned that participants would change their mind years down the road and not want their name associated with this research. To be clear, this is **not** a reflection of the ethics of the project, nor of your participation. From the very beginning of this project, I wanted to amplify the voices of people with hidden disabilities and acknowledge their agency and personhood, including using the name and pronouns that they preferred.

Since I want to continue to defer to your preference, I wanted to know your thoughts on the matter. As I see it, there are three options:

1. I leave your name as it appears in the drafted thesis, and work with the ethics committee to create a process by which people can remove their names later on if they so wish.

2. Change your name in the draft, to appease the viva team, but change it to a name **you** choose, so that you can still easily see your contribution.

3. Change everyone's name with names that I choose, again to appease the viva team.

As always, I want to be your advocate, so whatever your decision is, I will respect it and even fight for it if I need to.

Let me know which of these options you prefer, and I will act accordingly!

## 1.2. Participants' Responses.

**Alfie**: In my opinion you are the one who has done all the hard work, it is entirely up to you. You have worked really hard. I am happy with any, but if it is decided to change names to something decided by us, I'm happy to go by the name: *[redacted]* (my legal name come August).

**Amanda**: With regard to my name appearing in the document I'm of the opinion that I'm happy for it to remain. I'm not defined by my disabilities but there's no denying that I have them! I realise this is an academic document but having names in it gives it a more personal perspective in my opinion.
So I'm with option 1.

**Amy**: I am more than happy for you to keep my name in and i 100% agree that in this case it is important to have names in and not just get rid of the personal aspects of the people involved

**Ellie:** I would prefer option one, where I use my real name and pronouns, if at all possible - however if the majority prefer to be anonymised I'm happy to pick an alternative name to use instead. Thank you for asking, I appreciate being involved in the decision. Looking forward to reading the finished thesis!

**Jessica**: In regards to your question I really do not have a preference on which of the three options you choose, so I am happy to go with whatever the consensus is. Should you need it I am happy with option 3 where you can choose the name you change it to but I do agree with your hope of wanting to amplify the voices of people with hidden disabilities!

**Kasi**: I wish for you to leave me name and pronouns as I gave them to you (I'm honestly fine with any pronoun used within your work).

**Lisa**: I'm happy to be anonymous or named, whatever is easiest for you.

**Teagan**: Good afternoon,

I appreciate the courtesy of following up with us to see if we have changed our minds, however, I do find it quite troubling that the viva team would have an issue with the name section process. You were very clear that we were allowed to choose whatever name/alias and pronouns that we wanted.

I wish for you to leave me name and pronouns as I gave them to you. If you wish, you can try and figure out a process in which I could remove my name later on, however, I would hope that the removal of my name be by my choice and not by other people deciding what is best for me.

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609

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