Beyond the Stereotype:
Representing Disability in the National Museums of Great Britain

Thesis submitted for the degree of
Doctor of Philosophy
at the University of Leicester

by

Jennifer Eileen Hunt
School of Museum Studies
University of Leicester

2021

Abstract

Beyond the Stereotype: Representing Disability in the National Museums of Great Britain

Jenni Hunt

Disabled individuals form a large part of society, past and present, and yet are often overlooked when it comes to considerations of diversity both within the museum and elsewhere. Within this thesis I will explore recent museum representations of disability, examining the messages they embody and seek to convey.

This thesis focuses on three case studies: The Science Museum's *Wounded* Exhibition, The Museum of Liverpool's *Pioneering People and Places: The Blind School* exhibition, and the National Disability Arts Collection and Archive, examining for each the site, audio and visual material, websites, external communication, and interviews with staff. Together, these develop a holistic picture of the work carried out regarding disability stories.

This view is then evaluated, building upon work in both disability studies and museum studies. From disability studies, I draw on the social model, ideas of inclusion and emancipatory research; from museum studies, I explore issues around social justice, collaboration and co-creation. By combining these, I aim to gain a deeper understanding of how museums are successfully representing disability in a way that is of interest to a wide audience.

Throughout my thesis, I demonstrate the importance of working in collaboration with disabled voices in museums, acknowledging individuals' lived experience. In an original contribution, I also advocate and emphasise the importance of acknowledging the role of disability in our wider understanding of what it means to be human, linking to broader stories and themes.

This work is important as it speaks to inclusion and access. As I will argue, disability can best be understood as a part of humanity, so overlooking disabled people and their stories undermines museums' capacity to represent the richness and diversity of human life and leaves disabled people more vulnerable to ignorance and abuse. Museums can challenge stereotypes underlying negative attitudes, and I feel it is important that they do so.

Acknowledgements

The journey towards my PhD has been a challenging one, and one that I would have never got through without the support and care of so many people, who I wish to thank here for all that they have done.

First of all, to Richard Sandell, for his unwavering enthusiasm and encouragement throughout this project, and for believing I could do it even when I doubted it. His scholarship and support has been a driving factor for me, and his patience and wisdom got me through some difficult periods. I would also like to thank my second supervisor Sandra Dudley for her support and valuable comments, alongside thanking my initial second supervisor Janet Marstine, for her enthusiasm early on in this project.

I would also like to thank my interviewees, at all three of my fieldwork sites. Without their openness and interest in my research, it would have been impossible to move this project forwards. I thank Esther Fox, Kay Jones, Natasha McEnroe, Stewart Emmens, Charlotte Kingston, David Hevey and Alex Cowan for their insight and willingness to share their expertise. I was so lucky to work with such positive and knowledgeable individuals, and I hope that they find their words well presented within this thesis.

During my time at Leicester, I was lucky enough to be involved in work carried out by the Research Centre for Museums and Galleries, and I would like to thank those I worked alongside, for giving me the opportunity to explore topics and research which I care so much about: My thanks go out to Jocelyn Dodd, Suzanne MacLeod, and Sarah Plumb. The work I carried out for RCMG helped me to increase my certainty that this was the path I wanted to be on, and opened up incredible new opportunities. I would also like to thank Vicky Holmes and Simon Dixon from the university archives for the opportunity to work on listing items from the university's early years, providing vital archive experience and encouragement.

I wish to also thank the amazing community of the School of Museum Studies. In particular, I thank Christine Cheesman for her support, and Gurpreet (Bob) Ahluwalia for his humour, Suzanne MacLeod for her kindness and Nuala Morse for her smiles. Alongside this, I want to thank the PhD students I have been lucky enough to work alongside: Abbey, Chiara, Olatunde, Meredith, Aisha, Angela, Lulu, Minju, Blaire, Miranda, Cesare, Isabelle, Sandra, Bianca, Laura, Catalina, Eloisa, Kristina and so many others, alongside Jordan and Paige from History. Your support and friendship has made this journey that bit easier, and meant I never felt alone.

Finally, a huge thank you to my family and friends for their constant love and support throughout this journey.

To Alan and Nicki, for believing in me and supporting me throughout my entire academic path – without your advocacy, I would never have got past my GCSEs. To Elizabeth, for encouraging and inspiring me – you are the best sister I could wish for, and I am so proud of all you are achieving. To my late grandfather, for leaving the money that allowed me to pursue my dreams, and for believing that this would be right for me. To my housemate, Vicky, for listening and providing literally endless cups of coffee and hugs when they were needed, and then helping me get this into reasonable shape. To Liz, for helping me set goals and spending so many days in the pub working

together on our projects. To Rhiannon for your encouragement and belief that I could do this. To Lyndsay for your kindness and encouragement when I needed it most. To Russell, for giving me a PhD student I could lean on when the whole world turned upside down. To all my Brownies for helping life be fun. To the online communities that have supported me every step of the way, and letting me ramble about ideas (special thanks to Judith, Lavender, Midi, Lib, Fahre, Crou and Lourdes). And final thanks to Chrissy the cat, for being ridiculously cute and glaring at me whenever I get distracted.

Thank you all. Couldn't have done this without you.

Contents

List of Figures

Chapter Seven:
Figure 7.1: Lucky charms featured in the *Wounded* exhibition (Photograph by Jenni Hunt)

Figure 7.2: Repaired prosthetic leg within the *Wounded* exhibition (Photograph by Jenni Hunt)

Chapter One - Introduction

Purpose

The purpose of the research within this thesis was to examine how disabled individuals and their stories were represented in British museum collections, and to understand the driving forces behind such representations.

Disability often seems to have been forgotten about – and I aim to challenge this, considering the work that is being done by different sites, and exploring what would occur in the future around the representation of disabled individuals and their stories. As will be considered in more detail below, my motivation for this work was a personal connection to the topic. My interest combined with a sense that disability's role in history is often not considered relevant. This remains true even at a time in which more attention than ever is being paid to segments of society that have been overlooked in the past, and arguments relating to how museums can and should respond to past injustices are playing out across newspapers and online.

Research Questions

Having established the purpose of this research, I developed two key research questions, which are set out below:

> How are disabled people and stories of disability currently represented in exhibitions and displays within UK museums?
> and
> Which factors, aims and concerns shape these narratives?

These two questions helped to form the rest of the work that was carried out within this project. I have sought to examine current representations of disabled people and stories of disability within museums in the UK, addressing the underlying factors, aims and concerns which shape the narratives shared by the museums. The research aimed from

the beginning to both explore approaches to current representation, and to understand the reasoning behind it. I also hoped to consider the implications and impact that these representations have on contemporary debates pertaining to disability.

In order to fully investigate this, I created a number of sub-research questions. These could be broken down into two main groups – one concerned with the narratives and objects shown within the collection and the presentation of these, and the other focusing on staff attitudes and the role of museum representation. This latter area interlinked with wider debates within both culture and academia, about museums, social justice, and disability rights.

The questions considering representation within museums are:

- How are objects linked to disability presented within museum displays and exhibitions?
- What meanings and messages pertaining to disability can be discerned within museum displays, and how do these relate to narratives of disability that circulate in the broader mediascape?
- How has this presentation changed over time, and what factors have shaped this?

These questions examine what museums display and hold related to disability (as defined below) and evaluate how museums present these objects and their stories to the public in both physical and virtual settings. These questions could primarily be addressed by studying exhibitions and promotional material and comparing displays of disability within museums with representations of disability elsewhere, as well as with other topics represented by the museums.

The questions considering views and impact beyond the museum are:

- How do museum staff perceive disability as a topic for presentation?
- What aims lie behind the inclusion of disability-related material in museum displays?
- What challenges do exhibition-makers perceive in presenting disability-themed material, and what strategies are used to address these?

These questions explore the attitudes which shape the presentations discussed in earlier questions. They also consider the perceptions of museum staff of the impact which such

presentation may have on contemporary debates around disability and questions of representation. These could be primarily addressed by speaking to staff about the motivation driving their work, their goals, and the difficulties that they had faced. I return to this below.

Research Rationale

There were a number of reasons why I was drawn towards this particular research topic, both academically and personally. Academically, disabled individuals are often under-researched, even as disability studies pushes for disability to be seen as "a key defining social category on a par with race, class and gender" (Kudlick, 2003, p. 764). Disabled individuals are often overlooked, and historically have been hidden away – however, they account for a high proportion of the population, with all individuals likely to become disabled if they live long enough. As will be explored within Chapter Two, museums are increasingly working to support social justice, and to reveal hidden histories by unlocking stories that previously would have been concealed. It appears that if museums want to do socially purposeful work, they need to consider disability. However, at the time of writing and as I demonstrate later, it is still commonly overlooked even when issues of equality more generally are being highlighted. This gave me a strong academic reason to carry out my research, investigating an important and under-explored topic.

Beyond this, however, I was also motivated by my own experiences as a queer disabled woman, who wishes to see people like herself reflected within museum collections and exhibitions. I am autistic and dyspraxic, and these two factors combined to mean that, when I was younger, I spent a lot of time at historic sites and reading, rather than playing sports or socialising. This led to my lifelong love of museums. I care passionately about museums and the work that they do, and I believe that museums can be better than they currently are at telling stories around disability. Since 2016 I have been active on Twitter, running the @Our_Objects account which daily identifies an object linked to disability within museum collections. In both this thesis and my other practice, I wished to highlight examples of where this work was being done well, in order to show what was already being achieved and what else could be done.

Both academic interest and personal experience thus led me to this research and shaped my approach. This will be discussed in more detail in further chapters.

Key Terms

Before proceeding with the thesis, it is important to address how I am using certain terms that are core to the research.

Disability:

The Equality Act 2010 sets out that a person (P) is disabled if:
"(a)P has a physical or mental impairment, and
(b)the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities." (UK Government, 2010).

This definition matches that which is commonly used – with the Cambridge Dictionary (2011) defining disability as "an illness, injury, or condition that makes it difficult for someone to do the things that other people do". Definitions such as these place responsibility for disability on the individual, defining it as something that a person has, and which is a defect located within them. Many disabled people find such definitions both inaccurate and offensive, and turn instead to the social model of disability.

Social Model of Disability:

The social model of disability considers disability to be "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Barnes, 1992, p. 2). Again, there is an acknowledgement of the difficulties that a disabled person faces in taking part in activities. However, the emphasis has shifted: it is seen as something done to the person in question. A wheelchair user who is prevented from entering a building due to the lack of a ramp is disabled by the barrier that society has put in place, on top of the impairments that they may have (Cameron, 2015). Throughout this thesis, when I speak of disability I do so in the social model sense. Disability arises not just from an individual's impairments, but from society's attitudes and barriers.

There are still problems which arise from the social model, not least the fact it simplifies the experiences of many disabled people who find their situation deeply entwined with their impairments. However, I am looking in particular at how museums represent disability, and as I will return to in Chapter Five the social model can be useful for introducing key ideas around disability rights.

Disabled People/People With Disabilities:

Which of these terms is used varies between countries: the UK government's Disability Unit (2021) recommends the use of "disabled people", favouring identity first language, whilst the American ADA National Network (2018) recommends using person-first language, as "people with disabilities are, first and foremost, people". Within this thesis, I mostly make use of identity-first language, both out of personal preference and because I feel that due to the social model, disabled individuals are disabled by society. However, I acknowledge and use both terms within this work. Individuals who lack a disability are referred to throughout as "non-disabled people", again foregrounding their identity – within this thesis, it is their lack of disability that is relevant, as they do not face the same barriers disabled individuals do.

Representation:

When I speak of representation in a museum context, I am talking about visitors finding individuals like themselves reflected back in the objects held in exhibitions and collections and stories shown. In particular, within the context of this thesis I am discussing objects linked to disability that are displayed to the public. Outside of a museum context, I am talking about how people with disabilities are depicted within popular culture – how they are represented.

Structure of the Thesis

The thesis begins with an introduction (Chapter One) which sets out the guiding principles and aims of the study, explaining what will follow and introducing the key research questions and the motivation for the work. It serves to establish the project and set out a framework for the rest of my thesis.

Next, there are two literature review chapters. The first examines museum narratives of difference and social justice (Chapter Two), and the second takes a wider look at disability representation in the public realm (Chapter Three).

- Chapter Two (Museum Narratives of Difference) considers work being carried out around museums and social justice, starting off broadly with a consideration of human rights and then narrowing down to a focus on hidden histories, before narrowing further to museums and disability. The goal of this chapter is to consider the wider context of the work museums are doing around difference.

- Chapter Three (Disability Representation in the Public Sphere) considers why disability is a topic suitable for the social justice work of museums. It examines how disability is represented in the media, linking this to disability activism and the impact it has on disabled people's lives, before examining how museums have handled disability in the past. This focuses on the representations of disability and why it matters.

These two literature review chapters tie together to examine disability representation within museums, from both a museum studies and a disability studies perspective. Throughout this thesis, I will draw on both of these bodies of literature to move towards my conclusions.

After this, there is a chapter which focuses on methodology (Chapter Four – Research Methodology). This addresses the research questions in more detail and examines how the methods used were selected in order to best answer the questions given above, including explaining the selection of my case studies – the *Wounded* exhibition at the Science Museum, *Pioneering People and Places: The Blind School* exhibition at the Museum of Liverpool, and the National Disability Arts Collection and Archive (NDACA). It also considers the practical issues which emerged during the search for answers, and sets out how the data collected was evaluated in order to draw out key themes.

Next come four thematic analysis chapters, each of which focuses on a different element of the questions and of the research. The broad thematic areas emerged both from my research questions, and from the data.

- The first of these considers how disability is represented and the narratives which shape that presentation (Chapter Five – Narratives of Representing Disability), setting out the three case studies and explaining how they show disability in their spaces, language, media such as posters, and external communications such as websites. This is then linked to the different models of understanding disability. This theme emerged from the first of my two research questions, wanting to understand current coverage of disability. The chapter provides an overview of how the case study museums are presenting disability, and explains how museums are seeking to challenge the stereotypes which surround the topic and the narratives told.

- The focus then moves onto considering who is heard within these representations (Chapter Six – Collaboration and Co-Creation), examining the role of participation projects within museums, as well as examining the process of creating the exhibitions themselves. It explores how disabled people have been given voice in a range of different ways throughout the museum collections, and examines the difficulties and successes that this has brought for both museums and participants. This theme emerged from the data, and the presence of co-creation across the projects.

- Having examined the process of creating the exhibition, focus turns to the factors which lie behind the presentation of disability (Chapter Seven – Purpose of Presentation). This chapter explores the motivations and intentions driving the displays, considering issues of human rights, and the idea of presenting disability with purpose, all of which links to the work on the social model in Chapter Five, and the social justice work of museums covered in Chapter Two. Consideration is also given to what the audience is expected to gain from visiting the exhibition, and how visitors and staff respond to the exhibitions. This topic emerged from the second of my research questions, considering the concerns shaping narratives of disability.

- The last thematic chapter (Chapter Eight – Widening the Narrative) is an exploration of how these sites include disability within a wider understanding of diversity, and within the main body of their collections. It emerged from my data during the research. It tackles questions of integration and separation, and considers the future of displays of disability and what concerns and ideas will drive this work, including what has been learned by the staff within the case study sites.

The final chapter, Chapter Nine (Recommendations and Conclusions), provides an overview of what has been done, drawing out and reiterating key discoveries and their implications. It also considers the further work that could be done in the future, and the limitations of this project, in order to demonstrate what remains to be discovered to answer these questions.

In this way my thesis aims to answer my initial research question – examining the representation of disability and what drives it – building on both theory and my research to produce strong conclusions.

The aim of this thesis as a whole is to explore the work being done at this point in time concerning disability representation within museums, moving from theory to current positive practice, and then to build on it further in order to explore the changes that could happen in the future and to highlight key features of positive disability representation.

Conclusion

Throughout my thesis I aim to discover how disability is being understood and represented by museums, drawing on schools of thought from both disability studies and museum studies. Through a focus on contemporary practice, I hope to explore how museums' treatment of disability has changed, what has improved, and what still requires further consideration. I will explore the motivation driving this work and consider the key role that experience of disability is playing. I am discovering a change

in approach towards disability, with increasing attempts being made **to emphasise shared humanity** and, to varying extents, to show disability as a part of natural human diversity, alongside highlighting separate achievements in order to celebrate disabled lives. This connection with humanity as a whole has included an increasing focus on **collaborative work**, in order to enable voices with lived experience of disability to be heard.

Having set out my goal for this thesis, I now turn my attention to the first theory chapter, examining issues of human rights, social justice, and museums.

Chapter Two – Museum Narratives of Difference

Introduction

This is the first of two literature review chapters within my thesis. This chapter focuses on the ideas of social justice and human rights, considering how they are reflected within museums, and the work that is being done to advance these causes. Initially consideration will be given to whether museums should tackle social justice, followed by examining the range of ways that this is being done.

Having argued that it is necessary for museums to engage with the issues around social justice, I will examine the representation of hidden histories before shifting my attention to museums and disability. This analysis will include a consideration of the roles of human rights in understanding disability, and particularly focus on how museums can either help or hinder human rights work by their actions.

I aim to show that disability is an appropriate, and indeed essential, topic for museum work around social justice. I will then move on within Chapter Three to consider the often negative ways in which disability can be represented, and the impact such representation has upon disabled lives. This will show that negative representations have an effect on the individuals depicted in a number of ways, and consider how these could be approached differently. This reinforces the central thesis of this chapter – that museums have a role to play in examining and challenging negative representations, including those of disability, and ensuring more equitable presentation.

Social Justice and Museums

The idea of social justice in museum work is underpinned by the idea that museums can affect the struggle for equality (Sandell, 2019) – and can do so in either positive or negative ways. Depending on how they choose to frame an issue, museums are able to encourage their audiences to consider topics in new lights, and to examine ideas in a wider framework. Rather than simply reflecting back the society that they find

themselves situated within, museums are able to help shape it, encouraging discussion and reflection, and allowing for community connections (Streets, 2016). Such connections can help encourage an idea of shared humanity between different groups, encouraging and supporting visitors in making meaning.

The argument for social justice work in museums is therefore that museums have an impact on their audiences, and therefore the way that they approach challenging topics will shape the views of those who visit them. This can be done in a range of ways, but the arguments they put forwards are not ethically neutral. Museums hold stories about humanity, and by approaching them with a particular aim they can advocate for the rights of those they discuss.

Museums have approached issues around social justice in a number of different ways, attempting to engage various audiences and to examine a range of issues. As Sandell (2018, p. 182) argues, museum workers have to consider the effects and consequences of their actions, as they aim to engage with inequalities. It is claimed that if museums want to do socially meaningful rights work, they cannot continue with the status quo. Marstine (2011, p. 13) explains that in her view "the museum can be an ideal laboratory for promoting social justice and human rights" due to the nature of its purpose and the possibility of trying new things. However, in order to achieve this, a museum needs to engage with activism and "campaign to bring about political or social change." Marstine feels that museums need to take a particular position - and campaign for it - in order to cause lasting change.

This idea of the campaigning museum may feel very separate from the traditional view of museums' primary function, but for Marstine this role is instead a continuation of previous work. She draws parallels between this and the work museums have done previously in order to build a sense of statehood and citizenship. She also highlights that museums, whilst serving as repositories for objects (ibid., p. 7), are not alone in this – banks and private collections also hold a range of objects for safekeeping into the future. What matters, and what therefore distinguishes a museum, in Marstine's argument, is what is done with those objects – they are shown rather than hidden away, and used for education. If we accept this – that the fundamental role of a museum is not

simply to preserve objects, but also to make use of them – the relevance of museums for human rights work becomes clearer.

This socially purposeful understanding of museums is something that reaches across all the work that a museum does as they aim to tackle inequality and serve their communities. MacLeod (2018) considers how design can help serve this purpose, stating that museums can become urgently needed "vital, valued and socially impactful spaces for culture" (p. 14) if the user is considered from the start, rather than serving as an afterthought. Museums are able to share real and nuanced stories, serving as "environments full of possibility rather than displays full of information" (p. 25) – ensuring that the visitors benefit and enjoy discovering the issues that the museum is choosing to engage with.

Pursuing such work can leave museums open to criticism, leading to accusations of dumbing down or going against their purpose (Sandell, 2011, p. 131-134). However, as Filene (2017, p. 327) argued, museums have always been expected to use their collections to enforce certain views of identities. Museums cannot exist separately from their communities without being complicit in wider inequalities. Research has shown that museums are highly trusted institutions, with Ott (2010, p. 270) finding that 80% of visitors trusted museums more than books. This means that they are in a strong position to challenge dominant views and to "provoke, stimulate debate and expose visitors to alternative perspectives" (Sandell, 2011, p. 141). Museums are able to engage in challenging views, and in doing so they can reinforce human rights. A number of theorists (Sandell, Dodd, Jones, Marstine, MacLeod) have argued that museums need to place ethical approaches centrally within museum work in order to challenge and educate, as museums find themselves in a position where they have a high possibility of having a lasting impact.

Some of these possibilities were explored by Sandell's (2011) work on interpretive experiments across a number of sites, which aimed to offer visitors new ways of seeing and engaging in activist ethical approaches. He aimed to use these different methods to examine what worked well within a museum site, and to consider competing visions of what museums should be and do. He also wished to show that activist museum practice was "an entirely legitimate and increasingly important" approach (p. 130), tackling the

backlash that previous attempts at inclusion and access had faced, and addressing the social responsibilities and values of museums. Across the nine sites, the experiments aimed to offer "ways of seeing which subvert dominant (discriminatory, oppressive, stereotypical) representations", and instead provide visitors with new ways to understand the topic being addressed – in this case, disability.

This project, much like my own thesis, grew out from *Buried in the Footnotes* (Dodd, Sandell, Delin and Gay, 2004), which investigated how disabled people's lives were displayed and interpreted. It discovered that whilst museums held a wide range of material linked to disabled lives, there was an under-representation of this material in displays, due to concerns of how it could be displayed (p. 11). The representations that were found were "limited, often reductive and stereotypical", showing disabled people as passive and low-achieving victims (p. 13) or else overcoming their disabilities. The authors found that curators lacked guidance in how to represent these topics, and that without such guidance they didn't want to display objects and risk causing offence. By tackling different methods of approaching this topic, the research was able to help museums gain in confidence when hosting these displays, and to carry out important social justice work.

Hidden Histories

The idea of displaying so-called "hidden histories" is gaining importance in museums, as they seek to engage with a number of social issues, and to represent marginalised and ignored groups. Hidden histories is one term used for a number of stories that have also been described as contested, silenced, or difficult histories – histories that have not always been recorded, or displayed, due to taboos of either the past or present, or else a lack of information. These histories are 'difficult' for some curators, as they go against the stories they wish to tell, and are hidden because of a range of factors working together to avoid telling these stories.

Delin (2002, p. 86) argues that prejudices of the past limited the social roles available to disabled people, whilst modern curators are unwilling to engage in debate around disability, refusing "to search under the words 'deformity' or 'cripple' – which is where

disabled history is". By actively choosing not to address this area, this history continues to be silenced – not passively hidden, but actively concealed.

As Lennon (2018, p. 10) argues, "these stories have not simply fallen through the cracks of history, they have been pushed, purposefully erased or hidden away." Whilst Lennon is speaking about the lives of LGBTQ+ individuals, similar purposeful erasure has happened around the lives of ethnic and religious minorities, women, members of the working class, and, of course, disabled individuals.

Work aiming to engage in these histories is carried out often with the goal of making museums more reflective of the communities around them, and to increase visitation, however disability has often been overlooked (Sandell and Dodd, 2010, p. 10). Working to challenge this, in a way that allows for "genuinely collaborative and equitable processes of engagement" (Dodd, Jones and Sandell, 2017, p. 88), is a way that museums can move away from telling the story of the elites in culture, and instead approach the topic in a far broader and more meaningful way.

Such work would make museums more representative, and I believe more interesting. However, there are also strong ethical reasons for carrying out this work, much of which is foregrounded in ideas of human rights and equality. If, as is argued, museums are not ethically neutral, there is a degree of moral imperative for them to engage in challenging these absences, bringing hidden histories into the light.

Museums and Human Rights

Museums are increasingly addressing the topic of human rights, linked to the social justice work discussed above. Human rights are "rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status" (UN, undated). They set out minimum standards of treatment that all humans should be able to expect, based on the very fact that they are human. Everyone is entitled to these rights as a common standard across peoples and nations. The Universal Declaration of Human Rights proclaimed by the United Nations General Assembly in 1948 set out these fundamental rights for the first time. In the years since, further economic, social,

and civil rights have been developed, alongside conventions expanding rights to focus on groups felt to need additional protections, such as women, children, and disabled people.

These rights are significant as they set out legally enforceable expectations which apply to everyone, regardless of who they are or what challenges they face. Human rights may not always be respected, but they legally set out minimal standards of treatment for all humans, without question. This is significant as it implies an inherent expectation that all people should be viewed as worthy of dignity and respect, and supported in receiving such. Later, consideration will be paid to how exactly the Universal Declaration of Human Rights affects individuals with disabilities, but prior to that I will examine the relationship between museums and human rights.

As has been discussed earlier within this chapter, museums have increasingly been working towards being socially purposeful, to ensure that they benefit their audiences. This has led to an increased willingness to tackle topics outside of their traditional focus, and to consider stories around race, gender, sexuality, and disability. This is a movement away from museums that traditionally disseminated and encouraged traditional views of nationhood, above and beyond the life experiences of their visitors (Filene, 2017, p. 327). Over time focus has changed, highlighting resonances with visitors' lives, and moving from a collective sense of identity to a view of multiplicity. Museums now aim to serve as both "sites for individual, personal exploration of identity", and "places for reinforcing community identity" (ibid., p. 331) – although which of these is their key focus varies across sites. In a rapidly changing world, the museum can serve as somewhere that people can work together to discover a collective identity, and to work out what they want from society (ibid., p. 341). Playing such a role enables museums to serve as advocates for human rights, encouraging dialogues and promoting concepts such as tolerance and understanding.

The Role of Museums

I will consider the role of museums more generally, before examining how this can be applied to ideas around human rights. Museums have the capacity to "act upon and inform the social, political and cultural conditions" of the struggle for equality (Sandell,

2019, p. 169), encouraging their visitors to view things in new ways and consider topics within a wider framework. Streets (2016) argues that museum serve "to help us find ourselves, to see and be seen and to recognise that our future is built on the foundations of our past, the spaces we occupy, and our social relations" (p. 133) – this means that they serve as locations for both conversation and reflection, encouraging feelings of belonging and community, and allowing for connections. These connections can complement the idea of human rights, and help to develop the concept of shared humanity, making "the *I* into an *us*." (p. 134). Museums help visitors to create meaning (Avram and Burcea, 2016, p. 546), shaping what they expect and understand, and so this can be used in order to share certain ideas or advocate particular positions. Museums are not ethically neutral – they take a standpoint, and this has an impact on their visitors. Museums are locations that already hold stories about humanity, and by unpacking these with purpose they can take part in advocating for human rights.

Museums are increasingly taking it upon themselves to fulfil socially activist roles, as has been seen above. They are therefore working on drawing a stronger link between their work and its ability to protect and advance human rights – rather than claiming neutrality, they are taking stances on particular issues and trying to convince audiences of their positions. Having seen this and briefly considered the range of hidden histories that are being focused upon, attention now turns to the interrelation of human rights and disability.

The Rights of Disabled People

The UN's Convention on the Rights of Persons with Disabilities sets out the human rights of those who are disabled, emphasising the importance of inclusion. They are designed to ensure "the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN General Assembly, 2007). This shows clearly that individuals with disabilities are still considered to be entitled to the same rights and respect as non-disabled individuals, due to the basis of shared humanity. By signing up to this Convention, countries are agreeing to this idea in theory, even if it is not always executed well, or indeed at all, in practice.

Of particular interest to this thesis is Article 30, which sets out the rights for participation in cultural life, recreation, leisure and sport, emphasising the rights of disabled people to participate on an equal basis, including being provided with access to cultural materials, and stating that disabled people "shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity". As the United Kingdom is a signatory of this convention, there is an obligation to introduce measures that promote these rights and avoid discrimination (UN Enable, 2007). This can be seen as relevant to the work of museums, as they can support and acknowledge the culture and language of minority groups.

Disability is viewed as an equality issue in the Equality Act of 2010, in which it is listed alongside other protected characteristics such as sex, race and age. This makes discrimination on the basis of disability illegal, and also puts the onus on companies and groups to remove barriers that disabled people face (Soorenian, 2014, p. 74). This act works with the UN Convention on the Rights of Persons with Disabilities to try and encourage enjoyment and independent living, with full inclusion and participation by disabled people within work and society.

The social model has an important role to play here, as it casts disability not as "anatomy gone awry" (Gill and Schlund-Vials, 2014, p. 11), but rather something which is formed through exploitation and social barriers that are put in place. This means that whilst the Human Rights' approach does cast disabled individuals as vulnerable, it does so in recognition of the social position they occupy. Furthermore, this is done in order to ensure the inclusion and equality of disabled people, and to target and remove the barriers that the social model highlights. Unlike a humanitarian focus on disability which is based in charity (ibid., p. 6), the human rights model focuses on the idea that all individuals, including those who have disabilities, are entitled to be treated with respect and for certain foundational requirements to be met. Erevelles (2014) argues that disability serves as a materialist and historical construct, part of a wider understanding of what it is to be human, and what is considered unusual. Our social understanding of disability is based on what is required of society and what barriers are put in place, both from other people's attitudes and from the physical structures that surround us.

These socially produced barriers serve to prevent disabled people from experiencing the inclusion that their legal rights should provide for them. There is a distinction within the social model between the medical reality of the disabled person's impairment, and the disability created by social oppression (Titchkosky, 2014, p. 122). This clear division becomes far blurrier when applied to individuals' lived experiences, where both impairments and socially constructed barriers both have an impact. However, for museums that tackle prejudice, the social model can serve as a clear way of setting out potential barriers that disabled individuals face, and suggesting ways to remove them.

One example of the social barriers that disabled individuals face is the way that the media reports on stories around disabled individuals and benefits. These negative stereotypes, which go on to have an impact on individuals, are discussed in depth within Chapter Three. Disabled people find themselves framed "as outright benefit scroungers [at worst] or at best social burdens unable to contribute to society in any meaningful way" (Soorenian, 2014, p. 72). Discussions of disabled people being on benefits has often been framed as being a lifestyle choice, or a question of laziness, with money being provided viewed as an "incentive" not to work (ibid., p. 68). Soorenian found that between 2004-2005 and 2010-2011, there was an increase in disability-related articles within the media, many of which examined and debated the idea of benefits, and those who it was claimed took advantage of this. This negative coverage often combines with raised barriers for participation as support is removed. The media coverage of disability can lead to negative attitudes towards disabled people at the same time as raised barriers can make it harder for disabled people to exercise the rights set out for them within the UN Convention on the Rights of Persons with Disabilities (which emphasises full inclusion and participation) – and therefore tackling such negative stereotypes becomes a human rights issue.

As will be discussed within Chapter Three, the impact of this goes further than negative attitudes, with Soorenian discovering some disabled women were afraid to leave their homes due to "physical threats and accusations of benefit fraud" (ibid., p. 75). Soorenian claims that the coverage around disability in the media has led to a "highly inflammatory atmosphere" (ibid., p. 77) in which many disabled people become subject to harassment and hate crime, whilst also being "less likely than their non-disabled peers to find justice" (ibid., p. 80) due to fear of retaliation, struggles to articulate,

dependency, and crimes against them being dismissed by the legal system. Challenging these attitudes and presenting disability in a less negative way could potentially help to lessen these dangers.

Disabled people find that their human rights may be legally guaranteed, but that does not always mean that this is reflected in the social situations that they face. The existence of human rights gives disabled people potential recourse, but at the same time challenging negative attitudes is something that is difficult, especially when such negative coverage occurs and funding for legal aid has been cut, making it more difficult to challenge discrimination (Helm, 2019).

Disability Rights and Museums

Having considered the practicalities of these rights, my attention turns to how such a topic would apply within a museum context. Article 30 of the UN's Convention on the Rights of Persons with Disabilities states that disabled individuals have a right to access culture, and to be recognised and supported within their contributions to culture. This means that museums are faced with an expectation to represent their disabled audiences and to enable participation – something that is happening across certain sites, as will be shown within this thesis. Museums are also able to challenge negative attitudes, and in doing so work towards removing the barriers that disabled people face, ensuring that instead more positive and equitable attitudes are shown. In the literature there are a number of cases examining how museums have carried out human rights work in practice, and it is to these that I now turn my attention, before later considering how this work is carried out within the cases I address.

Sandell and Dodd (2010, p. 3) argue that representation has tangible consequences, with negative conceptions of difference shaping both policy and interaction, supporting what has been said before in this chapter. This gives motivation for museums addressing disability. At first, however, there was a focus on physical access (ibid., p. 10), rather than considering the nuances of disability, or ensuring that disabled people are shown within their collections. Sometimes museums put emphasis on ensuring they provide "minimum changes that will ensure legal compliance" (Smith et al., 2012, p. 63) rather than considering a broader commitment to the ethical underpinnings of full access.

Enabling disabled people to enter museums is important, but so is ensuring that they can find themselves reflected within it, as was argued by Majewski and Bunch (1998), who set out three layers of access – first physical access, and then access to exhibition content, before finally encouraging access "to our reflections in an exhibition" (p. 157), in which disability is included within the stories a museum shows.

Drawing on Majewski and Bunch's work, Smith et al. (2012) argue that museums need to go beyond minimal compliance, instead working to "facilitate a range of learning experiences and opportunities" (p. 64) and ensure that disabled narratives become "an established feature of cultural organisation's programmes" (p. 65), working to train staff and encourage an open dialogue with disabled groups in order to improve the museum's offering. To do this work, museum staff need to be familiar with ideas such as the social model, and confident in using them.

The social model has served as a powerful conceptual tool for museums, allowing them to take an activist perspective and give a moral argument, presenting a range of viewpoints. The Sandell and Dodd (2010) study spoke of how museums were able to use a paintings trail in Birmingham to layer perspectives, providing a range of commentaries that museums could engage with: a curator giving background to the work, links to contemporary disabled lives, and a personal response (ibid., p. 17). These multiple viewpoints did not aim to lecture, but to instead engage audiences, encouraging them to consider topics in new ways.

Across the world, other sites have also engaged directly with audiences on issues around disability. Chen (2010) examines the story of the Losheng Story Museum, in which residents who chose to remain at the site of the Losheng Sanatorium (where they had previously been confined due to leprosy) were empowered to share their experiences with visitors. In doing this, the residents gained support, and visitors were encouraged to reflect on the marginalisation that had previously occurred within their society (ibid., p. 244). Dealing with a potentially sensitive and challenging topic, the museum focuses on personal narratives, to allow communication and encourage "respectful ways of seeing" (ibid., p. 252). A group that was previously hidden away is

now encouraged to explain their contribution to culture, and to participate – in doing so achieving many of the goals discussed earlier within the human rights framework.

In 2011 there was an exhibition launched titled "Re-framing disability: Portraits from the Royal College of Physicians", which was carried out as a collaboration between Rethinking Disability Representation, the Royal College of Physicians (RCP), and the Research Centre for Museums and Galleries (RCMG). From its initial home within the RCP, the exhibition toured for several years, meaning visitors to a number of sites encountered it. The goal of the exhibition was to display the RCP's historic images of disabled people, which were viewed as "unique, artistically interesting, and had never been on public display before" (Telfer, Heaton and Anderson, 2011, p. 5) and to do so in a way that was respectful and acknowledged both the dark side of disability history and the social model.

Due to the topic matter of the exhibition, it was decided early on to work with disabled people throughout, in order to foster a sense of ownership, and to show disabled individuals as "parents, husbands, artists and professionals" (ibid., p. 6) who were not defined by their impairment, but were instead presented as entire and complete humans within their own right. The project aimed to consider emotional issues, emphasising the individual's agency and self-respect throughout. Work with disabled individuals took place in order to humanise disability and to encourage acceptance and celebration (ibid., p. 9), whilst acknowledging that "disabled people's experiences, identities and views about how they want to be represented are all different". Whilst this exhibition initially grew out from the artwork that was held in the collection, throughout the process the exhibition was treated in a way that aimed to respect the rights and humanity of all who were depicted, past and present.

The project relied on collaboration, sharing stories of independence and offering nuance, in an attempt to challenge negative attitudes. By researching the history around the portrait, it was possible to coax disabled people "from the margins of history" (ibid., p. 16), drawing out the autonomy of the individuals that were shown and highlighting how the images were of "people who did seem to have a degree of control over their lives, marketing their difference and capitalising from it" (ibid., p. 14). This challenged traditional historical views of disability, highlighting the agency of those depicted and

how they fitted within communities. It also aimed to prevent the viewing of people simply as medical exhibits – showing them as "active and independent" in their lives (ibid., p. 22), and highlighting their multiple identities, as parents and workers alongside being disabled – something which was often also emphasised within the images themselves.

The exhibition aimed to provide a different understanding of disabled people, showing them as celebrated and with the agency to "control the way that they were represented, in their clothing, their pose and their location" (ibid., p. 33). Connection was made between the lives of the individuals shown and the existence of disabled individuals today, by the display of modern images alongside historic ones. The goal here was to connect both groups, and to emphasise how disabled people had acted with agency both in the past and more recently.

The impact of similar work was considered by Dodd, Jones, Jolly and Sandell (2010) in their own study, *Disability Reframed: Challenging Visitor Perceptions in the Museum*, which aimed to support the audience of such exhibitions in gaining new understanding of key debates around disability. Assessment was by the way of a response card, asking "How does this display change the way you think about disability?" (ibid., p. 96). There were a range of answers, with many visitors willing to engage with what they had seen as can be shown below (Figure 2.1).
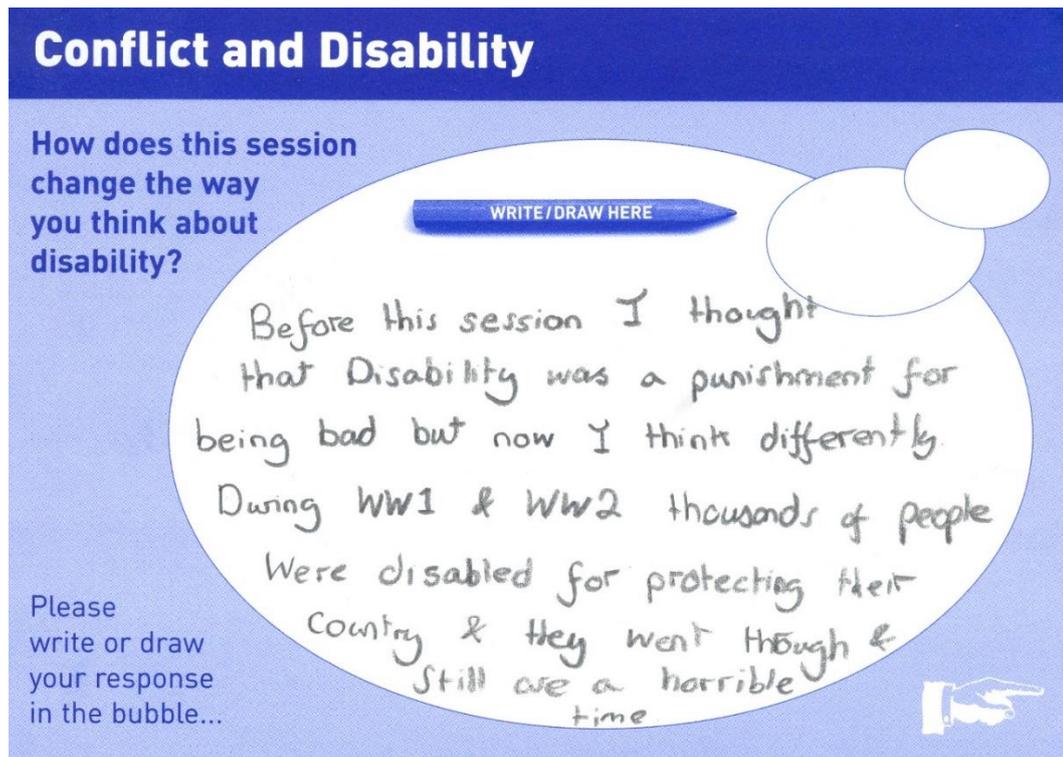
Figure 2.1: Response card for *Disability Reframed* (Provided by Sarah Plumb, RCMG)

Many of the responses focused on the authority that the museum provided, with the museum seen as being well-balanced in its coverage (ibid., p. 98). The authors used this to claim that museums can give visitors "credible and permissible ways of understanding disability" (ibid., p. 103), with the second largest group of responses focusing on ideas of rightness, equality and sameness. These ideas were often discussed using language that seemed outdated or offensive, but which showed an attempt by those who visited to comprehend the different views that were being represented. These responses were very immediate, as individuals had just seen the display, and this means they captured raw feedback rather than lasting changes in attitude. However, this change in perspective from visitors showed a willingness to consider alternative views, and to listen to stories around disability and human rights.

Based on current literature, it seems that museums are well placed to tackle human rights issues, due to the authority that they hold. Visitors are often willing to engage in the messages that are being shared, and this therefore can provide visitors with new methods of understanding even for stories that they believe to know well. There are numerous examples of how museums have engaged with civil rights issues around

disability, and this continues today, including within my case studies as will be explored throughout the rest of my thesis.

Museums and Disability

The inclusion of disability within a museum collection does not have to be carried out through a human rights lens, however. There are various other stories that can be told, either by including stories focused on disability, or making use of disability as a lens, and I would argue that including such stories would give a more accurate understanding of society and history than could otherwise be achieved.

Ott (2010) explored how museums could work with disability studies academics to share ideas, considering objects as polysemic (p. 271) and therefore able to be used to reframe and interpret narratives as the same object is used to share multiple stories. In doing so she draws out the similarities between exhibiting disability artefacts and "other areas of museum practice that embody ethical challenges" (ibid., p. 270), such as culturally sensitive materials and museums of conscience, thus highlighting how the objects could convey a range of ideas and address potentially upsetting and difficult issues. By drawing these connections, museums will then be able to approach these topics in shared ways, enhancing what they are able to offer to their visitors and making the stories which they are able to tell more realistic.

Ott addresses the fact that museums can serve as places where individuals can reframe what they know, with the tactile nature of objects allowing "sensory experience [which] is essential to knowledge, because words are limited" (ibid., p. 272) and therefore a gain in understanding. Here she draws on material culture research, explaining that material objects embody meaning. She considers what can be learned from the material objects of disability – giving the example of a sippy cup, which presumes the individual filling the item and using the item are different. In this way, the physical accoutrements of disabled lives can encourage learning about disability, drawing links and allowing learning through the senses and a deeper emotional understanding. She also emphasises the way that museums explore the variety of human experience (ibid., p. 275), whilst also acknowledging that disability is often overlooked even within sites that aim to have

a human rights purpose. She aims to make the link between disability and other groups more obvious, explaining how disabled individuals and museums can work together to create emotional responses in visitors in a way that makes knowledge more real for them.

This link between disability and other human differences was also explored by Kudlick in her 2003 article *Disability History: Why We Need Another Other*, which argued that disability should be seen as "a key defining social category on a par with race, class and gender" (p. 764). Rather than considering disability narrowly, she argues that disability is "so vast in its economic, social, political, cultural, religious, legal, philosophical, artistic, moral and medical import that it can force historians to reconsider virtually every concept, every event, every 'given' we have taken for granted" (p. 767) – by looking at disability, we need to reconsider our understandings of the world around us, and this is something that can only be done if we are willing to consider disability as part of humanity, rather than something separate. By including disability in a wider way, it becomes possible to integrate disabled perspectives within a wider narrative, rather than continually focusing on centralising non-disabled viewpoints.

Kudlick highlights the way that disability underpins much of social history, with many metaphors based in disability, and ideas of "idiocy and deformity" (ibid., p. 765) underpinning colonialist attitudes. At the same time, she highlights how disability allows intellectual exploration over questions over who counts as a citizen, what a community values, etc., with disability serving to "reveal and construct notions of citizenship, human difference, social values, sexuality and the complex relationship between the biological and social worlds" (ibid., p. 793). In this, she claims that disability is fundamental to society and understanding of humanity. At the same time, she states how certain disabled groups such as Deaf communities have been able to function as "active agents in their own fate" (ibid., p. 781), but only by drawing a distinction between their history and that of other disabled groups. Kudlick highlights the ways that disability challenges our understanding of humanity, and our view of history. It is only able to do this, however, if it is approached seriously and considered within the broader context of humanity, rather than being seen as an afterthought or aberration. In this way, she highlights how disability serves as a category "that in essence is commonplace, even seen as natural, yet treated as inherently abnormal" (p.

767). Disability is shown by Kudlick to be a part of humanity, but it is a part that is often hidden away or ignored, or else seen as separate.

Ott (2010) explains that some of the most interesting work in approaching other minority groups was done when it was possible to move beyond "redemptive recognition" (p. 270). Although this work is needed, the true learning comes when museums are able to move on and address contentious and complex issues, considering individuals from minority groups as "complex human beings who might have… committed unsavoury acts, or been flawed in some way" (ibid., p. 270). In this she explores how such work had been carried out previously with African American individuals, and considers how it might work with the histories around disability. By including disabled individuals as part of humanity and considering their stories from this perspective, more interesting ideas can be explored, allowing for a more complex view rather than a hero and villain binary.

Such benefits, however, do not mean that these stories are always shared. Indeed, Carden-Coyne finds that war museums often shy away from approaching this, although "physical and psychological disablement remain major legacies" of conflict (2010, p.64). For Carden-Coyne, this absence is because of intersecting prejudices (p. 69) and concern around offending. She also argues that a focus on conflict spanning particular dates means that longer impacts are often overlooked. However, she goes on to say that museums can enable discussion of difficult memories, and that the representation of disability is important within these sites. To fully tell stories of conflict, it is necessary to engage with stories around disability.

Therefore, it is clear that integrating stories around disability within wider narratives both allows consideration of what it means to be human, as explored by Kudlick, and an unpicking of more challenging and contentious issues as shown by Ott and Carden-Coyne. For museums that aim to address issues of humanity, human rights and social justice, disability has a vital role.

Conclusion

From the work examined in this chapter it is clear that museums have a part to play in examining and challenging negative representations that are prevalent in society. This is necessary for the human rights of disabled individuals to be respected, meeting the requirements of the UN's Convention on the Rights of Persons with Disabilities. Furthermore, such representation can enable progress to be made around issues of social justice. Such social justice work is something that many museums are engaging with, stepping beyond the idea of neutrality in order to take a moral stand and engage with key issues from an ethical viewpoint. I have argued within this chapter that the role of museums in society is dependent on this work, and I shall build on this throughout the remainder of my thesis.

As we have seen, museums can provide a range of ways of understanding disability. In doing so, they may provide alternatives to negative stereotypes that can often be seen within the media. It is to these stereotypes, and the attitudes and harms they can cause, that my attention now turns.

Chapter Three – Disability Representation in the Public Sphere

Introduction

This thesis examines the intersection between museum studies and disability studies, aiming to consider how these two areas can work together to guide representations of disability within museums. The last chapter examined how museums have tackled representations of difference, and how they have been working to explore the hidden histories of groups that have previously been overlooked, promoting the idea of museums being involved in supporting human rights and disability rights.

This chapter approaches the same end goal from the perspective of disability studies – focusing here on examining how disability is shown within popular culture, including a range of media and also considering representations within museums which can either support or challenge these stereotypes. Whilst the previous chapter examined the reasons for museums telling these stories, here the focus is instead on how these stories have been told. The last chapter showed that museums can tackle issues around human rights, including telling stories of people with disabilities and differences. This chapter aims to examine how disabilities are being shown within collections, and why this is important. Having set out some of the schema that exist for understanding disability representation, attention then shifts to why such representation matters – the impact it has on the lives of disabled individuals, and how representations link with ideas of human rights and social justice. Finally, considering all of this, the focus moves to a consideration of how disability has been presented within museums.

Having considered the literature around the representation of disability in museums both with a focus on museums, and with a focus on disability, it will be time to move on to the main body of my thesis, considering how disability was represented within the cases I examined, and the purpose of this presentation.

Disability in Popular Culture

Images of disability are widespread within our popular culture – with sources such as books, films, television and music all reinforcing certain ideas about what it means to be disabled. These representations often use disability to invoke stereotypes or as a narrative device in which the disabled are "blessed or damned but never wholly human" (Gartner and Joe, 1987, p. 2). This contrasts with more realistic depictions of disability as a characteristic of an individual with their own lived experience. My aim here is to consider the range of representations, the impact that they have, and the importance of such work.

Within recent years the field of disability studies, and activism by people with disabilities, has led to a shift from the medical model of disability to the social model. In doing so, the focus has altered from viewing disability as an individual tragedy that needs to be fixed by doctors to recognition of the wide variation to be found within humanity, developing an understanding that all people have a mixture of limitations and strengths (Gartner and Joe, 1987). In this view of the world, it is society which causes disability by placing barriers in the way of a person with an impairment. It is these barriers which disable the individual, and therefore it becomes the task of society to remove these and enable access in order to restore the equality that would have existed if not for the barriers being in place; this understanding means access is viewed not as an act of charity, but instead a restoration of rights which society has taken away (Church, 2006). However, this model is not reflected to a great extent within the media, which often instead portrays views of disability which return to the medical model (Riley, 2005), placing the blame squarely on the individual depicted and their differences rather than wider society.

Below, I consider some of the common ways that the media portrays disability – as villainy, as victimhood, as spectacle and as inspiration – using examples from popular media (the films, books and stories which are influential in shaping how people understand particular ideas). Having set out these examples, I will then turn to the different framings that have been developed and how they interlink with historic experiences of disability.

Disability as Villainy

The traditional villainous portrayal of the disabled individual is that encapsulated by Shakespeare's Richard III – a man driven to vengeance and fury due to his disability (Gartner and Joe, 1987). He is not the only example of this – figures such as Ahab, the Phantom of the Opera and many of James Bond's villains loom large in popular culture. In these images, we see a repetition of the medieval world view that links "deformity with moral corruption" (Hickling, 2017a). Frequently in popular culture disfigurement and disability are linked to villainy and bitterness.

This link between disability and evil is particularly shown in media representations of disabled sexuality in which "disabled characters convey a kinky, leering lust for sex with gorgeous 'normal' women" (Longmore, 2004, p. 141), with disabled characters shown as stalking, harassing and otherwise assaulting non-disabled women. In this way disabled individuals are shown as threatening and menacing – one of the few exceptions to the common portrayal of disabled people as sexless. This threat to 'normal' women can also be seen within the horror film, as the disabled individual wreaks havoc as retribution, further linking social stigma to bodily difference (Snyder and Mitchell, 2006). In this way disabled bodies are used as the "repository" for society's sense of concern about the vulnerabilities we all possess (Garland-Thomson, 1997, p. 6). Placing disabled people into the villain's role is used as shorthand in popular culture for the fear of becoming disabled, using the disabled individual's disability as the defining characteristic about them, and showing that they are monstrous inside and out.

Alongside this understanding of disability as an essential, evil and defining characteristic of the individual, there is also a widespread belief that many who are claiming to be disabled are in some way 'faking it'. This is a very different kind of villainy, one that is seen as 'taking advantage' of people's kindness and pity by feigning impairment. This is a view which is supported by rhetoric in the media discussing 'benefits cheats' – the concept that an individual who is disabled is "just being lazy to get benefits, support and services" (Hadley, 2016, p. 677). This view ties in with misunderstandings about the experience and abilities of disabled people, leading to non-disabled individuals acting as "self-appointed diagnosticians who see themselves as the social performance police" with responsibility to stop fraud (ibid.). Such actions place

disabled individuals in danger and disrupt their lives, as will be examined later. Certain disabilities become viewed as 'personal failure', for example an individual who is obese often faces judgement for their lack of self-control, without consideration of the wider circumstances (Turner, 2006). These accusations are made by individuals who have experienced only fleeting glances of the disabled person, yet feel authorised to pass judgement due to attitudes they have seen reflected within the media.

Alongside interrogation and public confrontations, individuals with disability can often become the target of online 'memes' aimed at humiliating and challenging them for faking their identity. One such example of this, which Hadley (2016) draws attention to, is the image of a woman standing from her wheelchair to reach a high supermarket shelf, which is captioned "Alcohol: Makes miracles happen" – with the implication being that she is faking her condition, and can discard it when it is beneficial to her. This meme can also be viewed as showing a paternalistic attitude to people with disabilities – implicit within it is the idea that she should be mocked for buying alcohol, which is perfectly normal for any adult (Evans, 2013). This tendency to infantilise those who have disabilities will be further discussed later.

Disability as Victimhood

Moving on from the view of disabled individuals as liars and villains, another common stereotype which has been applied to this group is that they are to be pitied, and that their lives are of little value. In the past it was believed that disability was a "divine punishment" (Cox, 2012). This in time gave way to the medical model, where disability is instead best understood as something to fix – an inherent flaw in the individual. This links to the concept of eugenics: in 1927 a film called "Are you fit to marry?" used the possibility of a disabled individual having disabled children as a reason for sterilisation (Snyder and Mitchell, 2006, p. 170). Indeed, the media has been used in a number of contexts, most notably America and Nazi Germany, to argue that people with disabilities should not be allowed children – and in the most extreme cases to argue that they should not be allowed to live. Popular support for mass sterilisation and mass murder was built on representations of disabled individuals as inferior and unworthy of life – disabled people have faced serious consequences for such portrayals.

Whilst such blatant views are rarely expressed in Western popular culture today, the legacy of such ideas lives on. In 2016, the film *Me Before You* was released, telling the story of a wealthy man who was paralysed in a motorcycle accident. Despite the support of his family, glitzy parties and a romantic entanglement with his carer, he chooses to travel to Dignitas in order to die, leaving his carer with his money. The story is told through the eyes of the non-disabled carer: "through caring for the disabled man she finds both love and a reason to experience life" (Lopez, 2017). It was a box office success, winning the People's Choice Award of 2016 for "Favourite Dramatic Movie", but was heavily criticised by disability groups for its portrayal of life with a disability – in particular for implying that a disabled person is a burden on their family, and that his suicide is a mercy as he is 'better dead than disabled'. This idea that death is the only answer to life with disability is repeated in many popular films (Gartner and Joe, 1987), either as the disabled individual's punishment or as a tragic and inevitable necessity.

The language used to describe disabled individuals often also encompasses the idea of pity and charity – for example when someone is described as 'suffering from' a condition, or described as brave simply for living their life – an idea examined in more depth below. Charities have often represented disabled individuals as objects of pity, in order to increase their revenue. These campaigns tend to cast disabled individuals as the passive recipients of aid, and consider disability to be an issue of the body, rather than a condition caused by society (Riley, 2005) – with money often being raised for medical procedures rather than attempting to change attitudes. Whilst some charities are now working more with disabled individuals rather than speaking for them, this paternalistic view is still visible, and heavily criticised by disability rights groups for being patronising and discriminatory, with traditional charity representation creating "images of disabled people which suggested infantilism, dependency, passivity and need" (Sandell, 2011, p. 144). Such images further enhanced the idea that disabled people are primarily victims, rather than individuals able to act with agency.

Disability as Innocence

Another negative representation that disabled individuals face in popular media is being used as a representation of purity, or childlike innocence. The vulnerability of disability, and in particular the vulnerability of disabled women, is shown in the subgenre of

slasher films in which blind victims are used to invoke the idea of vulnerability in the audience (Snyder and Mitchell, 2006). Rather than monsters, disabled individuals are here shown as helpless, leading to people misjudging the capacities of disabled people that they may meet in their life.

Within Hollywood films, adults with intellectual disability are rarely shown, and yet for many people this is their only experience of such people, and the films therefore "inform public and professional perceptions about desired and appropriate occupational participation", as stated by Renwick, Schormans, and Shore (2014, p. 29). Their research showed that individuals with intellectual disability were often portrayed in an infantilized way, with the tasks they are shown undertaking being greatly simplified. Adults are shown acting in a child-like manner, or doing child-like actions – one character has a bedtime story read to him by his six-year-old daughter. The tasks shown within their occupations are also simplified, leading to an underestimation of the ability of disabled individuals alongside a denial of their sexuality and adulthood (Evans, 2013). The harmful impacts of this on the lives of disabled people will be considered in more depth further on in this chapter.

Disability as Spectacle

Disabled people are frequently used to create visible spectacle within both cult and fantasy films. The idea of spectacle is key to cinema, and in particular cult films and exploitation films (low quality movies aiming to succeed based on lurid content) have repeatedly used freakery to show images that were taboo, aiming to shock, horrify and titillate audiences – and in doing so further marked out the disabled body as other (Church, 2011). This presentation can have harmful consequences, as will be seen later, and cause isolation for disabled people more widely. However, much criticism of this type of film, like criticism of the freak show before them, centres around outraging public decency rather than concern for those who are shown (Church, 2011).

The concern is that by seeing individuals like these, the viewer may be distressed or shocked – an idea which again establishes the disabled body as taboo and monstrous. Such attitudes further other disabled individuals, implying that they should be hidden away from public view, something which was historically practiced with the incarceration of disabled individuals in institutions. Even enjoying cult and horror

genres can taint the audience with accusations of a "deviant mentality akin to mental illness or even insanity" (Church, 2006) – and fans of these genres often relish their own temporary enfreakment rather than support the cause of those disabled individuals who no longer wish to be viewed as other.

Alongside cult and horror films, another area of cinema where disabled bodies are prevalent is the fantasy genre. Disability here can often serve merely as set-dressing, with disability as 'strangeness' showing the extent of the fantasy world (Church, 2006). Again, there is therefore the implication of otherness and a lack of humanity as disabled individuals often play non-human characters such as pantomime dwarfs, rather than leading human roles.

One fantasy film which deals directly with the idea of disability is *Edward Scissorhands* (1990) – Tim Burton's gothic tale in which the protagonist is an unfinished creation who has scissors in the place of his hands. His story is one about the importance of looking past appearance, yet his disability is "symbolic of an inner emotional deficit – feelings of exclusion and an inability to be understood and loved" (Church, 2011). We see the reactions he faces as he ventures into society, with some people repulsed by him, others wanting to cure him and others wanting to use him only as a tool. In this, he experiences a number of reactions common to people with disabilities. The story humanises the monster, but in the end it is his monstrous nature which overwhelms him as he accidentally kills someone and he finds himself retreating back into the darkness that previously defined him. Therefore, he is again removed from society, and whilst the narrator shows her sympathy for him it is clear that he is neither welcome in, nor suited for, society. In this way a film which shows a disabled individual in a mainly positive light again ends up condemning them to solitude, and framing such solitude as the correct place for them.

Across these genres of film, disabled individuals are often represented as markedly other from 'normal' non-disabled humans, and it is implied to a greater or lesser extent that they are not fit for society – that their difference is too great for them to be welcomed – be that because they are too monstrous, too evil, or too vulnerable. This attitude, reflected across the media, is harmful as it may lead towards alienation and isolation, cutting disabled people off from society as a whole.

Disability as Inspiration

After these various portrayals which are clearly negative, portraying disabled individuals as monsters, naïve children, or in a significant way not-human, there are also portrayals which at first glance may appear more positive, but which can still cause harm: ones which show disabled individuals as people to be looked up to, or as in some way above other people and better than them. However, as Riley (2005, p. 2) argues, it is "just as tiresome to be looked up to as to be looked down on, and in both cases one's appearance is altered", and the stereotypes that are used here bring with them their own injury. These views are damaging as they ignore the simple humanity of the individual shown, raising them on a pedestal where they can be used in order to criticise others, and facing judgement themselves when they fall short of the impossible standard that has been expected of them.

One of the most common representations of disability seen in the media today is the image of the disabled individual as an inspiration. Hartman (2012) challenges this, saying it is offensive as it 'mythologises' those with disabilities, returning again to black-and-white heroes versus villains stereotypes, with the message being "They're heroes because, well, look at them". Whilst images of inspiration are often shared by people who wish to support disabled individuals, it comes across as dehumanising and patronising, leading to criticism as "inspiration porn" which tells non-disabled individuals to try harder and guilts those who have disabilities and do not succeed in this way (Building Radical Accessible Communities, 2012). This has led to a push back from disabled individuals, such as Stella Young's (2014) TED talk in which she criticised the fact that "for lots of us, disabled people are not our teachers or our doctors or our manicurists. We're not real people. We are there to inspire." She then goes on to explain that this is a lie, and to criticise the attitude that brings it about, and the expectations such beliefs create.

It is important to acknowledge that some disabled individuals do remarkable things – but the emphasis needs to be on these achievements, rather than the fact that they are living whilst being disabled. An example of this would be the athletes in the Paralympics, who are elite sportspeople. Such achievement is worth admiring, but it

does not mean that all disabled people are able to achieve (or indeed interested in achieving) such feats. The Paralympics have been found to have had a large effect on the public's attitude to disabled individuals, with a Channel 4 survey showing that 65% of respondents felt that the 2012 Paralympics had a favourable impact on people's perceptions of those with disability (Channel 4, 2012). This is particularly because the broadcasting of the Paralympics was accompanied by an attempt to include more disabled presenters in the coverage, linking to the discussion of participation that happened within the last chapter. Effort here was being made to normalise disability, rather than othering in the way that showing disabled individuals only as inspirations can do.

Elsewhere however, the representation of disabled people can feel tokenistic and patronising. One example of this would be the inclusion of disabled children in online collections of heart-warming moments, where they are included simply because they are disabled – for example a photograph of a child's Halloween costume including their wheelchair. In this, the only remarkable thing about the child is their use of a wheelchair, and so disabled individuals are given "the same role as a puppy stranded in flood waters" (Bunnika, 2012). This can be seen as both insulting and dehumanising, rendering the disabled person living their life as something to be admired simply for existing.

Inspiration porn is often seen online – photographs of wheelchair and prosthesis users, often with captions such as "the only disability in life is a bad attitude". Such attitudes are viewed as both tiresome and damaging by many in the disability community, as they aim to persuade non-disabled people to achieve their goals by showing the capacity of disabled people. In this way the disabled individual is reduced to their prosthesis (Willitts, 2017), and the blame for disability is placed on the individual, and in particular on the individual's attitude. Willitts highlights the issue with this by pointing out that such a slogan is the equivalent of saying "you could be cancer-free if your approach to life didn't stink". Such attitudes link to the benefits-cheat idea discussed above, placing the blame for disability on the disabled individual. If a disabled person struggles, inspirational representations seem to say, they are the one at fault for failing to rise above their impairment. Some disabled people manage to achieve more, and therefore those that do not are viewed as failing for not having the same successes – for

all that very few non-disabled individuals do things such as run marathons or compete internationally in sports.

Such images also suggest that there is no need to remove societal barriers, as they imply that someone with a positive attitude would be able to manage their disability – a claim that seems ignorant at best, and cruel at worst. Stella Young (2014) challenges this, pointing out that "no amount of smiling at a flight of stairs has ever made it into a ramp." In some cases the tendency for such pictures to go viral has led to their monetisation, with images of disabled children used in order to farm likes and create profit (Ellis, 2015). This further objectifies the individual as their lived experience is now being used simply to manipulate the public, often with no benefit to the person shown, and indeed causing widespread misunderstanding via a misrepresentation of their life.

Alongside the emphasis on simplified physical achievement shown in attitudes towards disabled sportspeople, there is the common concept of compensation – that those with disabilities are rewarded by special gifts (Gartner and Joe, 1987). This can often be seen in people's understanding of conditions such as autism, spread by films such as *Rain Man* (1988), but also within the story of the comic book character Daredevil – the story of a blind man who "fights injustice by day as a lawyer and by night as the Super Hero Daredevil" (Wong, 2015). Whilst the television presentation of him attempts to show aspects of his disability realistically – with a tactile wristwatch and self-deprecating humour about his condition – his other senses have heightened, enabling him to act as a human lie detector.

Although showing a visually impaired superhero is positive in terms of disability representation, the fact that the series was not initially audio-described came in for widespread criticism (ibid.). In response to a campaign Netflix did provide audio description. However, the fact that it was not considered prior to release can be seen to indicate that real disabled individuals were very much an afterthought. The lack of consideration for a disabled audience, even in a show where the central character is disabled, shows yet again how disabled individuals are marginalised by society.

Disability as Humanity

Having considered a range of presentations of disability within the media, both those which are clearly negative and those which contain problematic aspects, attention turns towards the more realistic portrayal of disability – a chance to show disabled individuals as human, and as active rather than passive in their own lives.

Such a view would be more similar to the experiences of real disabled people than those that have been discussed above. It would also be more accurate to our understanding of humanity, and what it is to be human. Despite our overwhelming image of the past as full of healthy and non-disabled individuals, as perpetuated in the media, until recently the "most common physical traits included being arthritic, stooped, pock-marked, scarred, toothless or bent and injured in some way" (Ott, 2005, p. 21). Showing such disability in representations of the past would lead to a more truthful understanding of our shared history. In addition, considering the difficulties and barriers faced by disabled individuals respects their embodied experiences – this is seen within disability documentary cinema, which collaborates with disabled individuals and is often disability led (Snyder and Mitchell, 2006), and in other aspects of the disability arts, more commonly than within mainstream media.

One relatively recent mainstream representation of disability was an advert broadcast during the 2012 Paralympic games, using humour in order to sell chocolate. This put disabled individuals at the front of advertising, and was a success for the brand (Maltesers) with sales growing 8.1% and brand affinity by 20% (Mortimer, 2017). Its success led to the company choosing to look further at difference, whilst trying to ensure that they have the diversity they are showing reflected in the creation of the advertisements – involving disabled people in the development of scripts. Despite this attempt to work with the disabled community, it has been criticised by some people for its trivialisation of disability, and the focus being on education (Pepper, 2016). Criticism has also been raised about the way it presents the sexuality of disabled women as something naughty, with the viewer presumed to be an outsider. Despite its possible flaws, this advertisement represents a move from showing disability as a symbol, and the focus of a disabled individual's life, to showing it as an aspect of an individual – a

feature of their life, but not the sole reason for their inclusion in a show and not the centre of every storyline.

Although disabled actors are infrequently used in advertising, there has been an increase in representation – often within themed advertisement breaks (Vizard, 2019). Meanwhile, soap operas are increasingly including disabled actors within their cast, such as Lisa Hammond, who plays Donna Yates in EastEnders, and giving them storylines which stray beyond the traditional roles given to disabled individuals. This helps to humanise disabled individuals, as here they are shown as a part of a community, rather than being simplified to their disability.

In 2002, Delin argued that by ignoring the existence of disabled individuals in the past, or else restricting them to only certain roles, museums serve to narrow people's expectations (p. 84). By not showing these stories, there is no sign that disabled "people like themselves lived, worked, created great art, wore clothes, were loved" (p. 85), and such representations are greatly limiting. Rather than these absences, she argues that it is vital disabled individuals are presented as "as much part of British culture" (p. 96) as anyone else. By acknowledging the historic existence of disabled individuals among both the extra-ordinary and the ordinary, a richer understanding of the past can be developed.

Artists, disabled and non-disabled, have also engaged with the depiction of disability, both historically and in contemporary settings. Garland-Thomson (2010) examines how elements of classical portraiture have been used to confer dignity and respect on disabled people, showing them as valued both in the framing of the image, and in its very existence. Mat Fraser became the first disabled actor to take on the role of Richard III in 2017 (Hickling, 2017a), and in doing so brought his own life experiences to the role. In particular, during interviews he spoke of empathising with Richard as someone for whom the normal routes of advancement are closed off. Fraser was praised by critics (Hickling, 2017b) for playing on his outsider status, and showing his awareness of not fitting in. In this way, a disabled actor was able to challenge expectations and bring greater awareness to the audience – the inclusion of his disability deepened the portrayal and made it more relevant.

As technology continues to advance, and disabled individuals become both consumers and creators of social media content, they have been able to create their own memes to challenge popular narratives around disability: for example "one does not simply go out at night… when in a wheelchair", or Cohen-Rottenberg's (2013) tongue-in-cheek "see the person… not the normalcy" images. These aim to get people to laugh and to think about disability in realistic terms (Hadley, 2016), highlighting the flaws in some popular representations of disability. However, these are often shared only among the disabled community – building their own identification, but not challenging broader narratives. Some memes however have spread further – such as the "This Is What Disability Looks Like" Facebook group which has thousands of people involved, and which spreads their message far wider, aiming to help people gain a wider understanding of what disability is, and who it affects. By doing this, the group is able to challenge stereotypes.

However, just because this content is being created, it does not necessarily elicit the response intended (or desired) by its creators. For example, a statue of the artist Alison Lapper, who was born without arms, faced criticism when exhibited as part of the rotation of artworks on the Fourth Plinth in Trafalgar Square. It was described as a "drab monument to the backward pieties of the age" (O'Neil, 2007), with the commentator contrasting his admiration with Alison Lapper who has "overcome great challenges", to his revulsion at the statue. Not only here does he ignore the importance of the statue of the pregnant Lapper as a celebration of disabled women's sexuality, a topic often ignored, but it also expresses the same pitying views that were discussed above.

Similarly, the inclusion of Cerrie Burnell, a disabled presenter on CBeebies (a television channel aimed at younger children) led to unpleasant comments online, with Burnell being told she would give children nightmares because of her limb difference (Dowell, 2009). However, Burnell used this hatred as an opportunity to start a discussion on the media's focus on the perfect body, and was able to therefore reclaim her image. The inclusion of disabled individuals within the media for reasons other than their disability is a rare occurrence, but one that can challenge people's views and the stereotypes that they hold, as will be discussed later.

Representations of Disability

Over time, representations of disability have altered, and continue to change. One schema for this, suggested by Garland-Thomson (2010), will be contextualised historically later in this chapter. Although some negative stereotypes remain, they are no longer the only images available for disabled individuals. The nightmarish disfigured monster still looms large in popular culture, alongside the recently paralysed man who would rather die than live on with his disability. They stand alongside those celebrated as inspirational for feats that would be unremarkable if performed by non-disabled individuals, and adults who are viewed in culture as asexual children, pure and simple both in understanding and in their role within life. However, more recently they have been joined by a cast of other characters, both fictional and real, who present a more nuanced explanation of disability.

Calls for better disability representation must not be mistaken for calls to cast all disabled characters in a positive light – Matt Fraser's ground-breaking portrayal of Richard III depends on his characterisation as "an evil fucker" (Hickling, 2017a). Instead, they are demands to allow disability to be acknowledged as part of an individual's character, rather than the only feature of their existence. Here links are also made to the social model, and to wider demands that portrayals of disability expand beyond the view of disability as a medical issue or personal tragedy, to instead consider disability as a social condition. If this is done, then consideration is given to social attitudes rather than medical intervention, and so the stories that are told can be very different.

The voices of disabled people are starting to be heard, as priorities shift and people find new ways of speaking out. These new ways are far from flawless – with an increasingly graphics-based web meaning that those with visual impairment finding themselves cut off from access (Ellis, 2015), and all too often their content reaching only those who already agree with what is being said in an online echo chamber (Riley, 2005), but these new methods still present a valuable opportunity to challenge mainstream narratives.

At the same time, there is always the risk that narratives focused on normalising disability can stray too far, denying the reality of lived experience in an attempt to pass

disabled characters off as the same as everyone else (Garland-Thomson, 1997), and in doing so silencing the very calls for change that have brought us this far. This links to wider issues with the social model, which can be seen as ignoring the significant impact that impairment has on some disabled individuals' lives (Shakespeare, 2014).

Progress isn't always clear cut, but media and popular culture can focus passion and highlight issues (Ellis, 2015), humanising those who have for far too long been denied and hidden away. With the active involvement of people with disabilities in the creation, production and consumption of media, and the persuasive power of media clearly demonstrated, it seems hopeful that such progress will continue across a range of representations, leading to wider changes in attitude.

Impact on Disabled People

Having considered how disabilities are represented, attention turns to why such a thing would matter. If such portrayals have no impact on their audiences, it would arguably not matter how physical and mental difference is portrayed. As claimed by Shakespeare (2014), images portrayed in the media can and do shape the fate of disabled individuals – the way people are shown impacts not only their own belief of their capacity, but also the beliefs of others. An individual representation may have little impact, however when combined with other similar views a "dominant regime of representation" (Hall, 1997, p. 269) is created which offers a set vision of the people and events it documents. This dominant representational paradigm is a representational system that presents a certain opinion of those that it represents. This constructionist view considers how culture helps produce and transmit meanings, and in doing so governs social practices and conduct. Hall argues that common representations shape how society views particular groups. Hall's research focuses on race, however his research can be applied more broadly.

Hall presents three methods for countering these views – reversing stereotypes by valuing the difference that the group is commonly criticised for, presenting positive images (something which can be seen within "inspiration porn" as those who are normally looked down on are instead held up as something to admire), and challenging representation from within – rather than avoiding controversial topics this aims to use

the stereotypes against themselves by encouraging looking and in doing so de-familiarizing the body and challenging assumptions. While some of the work discussed above does achieve this, it does not do so in a high enough quantity to drown out the voices dominant in the representation of disability – representation entrenched in the medical model.

If the media presents people with disabilities as falling into certain roles, these images will restrict the lives of people who are disabled by shaping the attitudes of society, and indeed their own images of themselves. The media's representation of disability is particularly significant as 42% of non-disabled people claim not to know a disabled person (Mortimer, 2015). The media is where non-disabled individuals come into contact with people with disabilities, and the stories that they are shown will shape their attitudes towards disability. This is proven by a study which showed that a positive representation of disability – in this case a short film showing a police officer with spinal cord injury – could affect the view of a non-disabled audience. Having watched the film, the number within the non-disabled audience who believed a police role could be suitable for someone with a spinal cord injury increased from 30.1% to 49.5%, and estimates of the employment figures for people with disabilities increased (Reinhardt, Pennycott and Fellinghauer, 2014). Whilst this study only looked at short-term attitudes, it is still an interesting example of how portrayals can change the public's view.

Such impacts are not always positive. A study by the Leicester Hate Crime Project (2014) showed that 90% of disabled respondents had experienced verbal abuse, and 97% feared future verbal abuse. Furthermore, 88% were afraid of experiencing violence directed towards them as a result of their disabilities. Indeed, it seems that hate crime towards disabled individuals is increasing, with a 41% rise between 2014 and 2015 (Mortimer, 2015) and a further 101% increase between 2015 to 2017. This has been joined by an increase in hate crime towards disabled children – from 181 incidents reported in 2015 to 450 in 2016 (Kiteley and Robinson, 2017). In a climate of growing hostility, realistic representations are more necessary than ever.

Non-disabled individuals who have seen disabled individuals presented as cheats may feel entitled to assess the abilities of someone with disabilities. This has led to disabled individuals often becoming adept at answering questions about their conditions – an

additional burden when people are simply trying to live their lives, with sometimes quite intimate questions being asked by total strangers. The expectation to educate or else risk being seen as bitter and resentful is an added labour for disabled people (Gartner and Joe, 1987), and one that can be avoided by the inclusion of positive representations within the media. In addition, due to lack of understanding about disability, disabled people find themselves facing pressure to either be 'completely disabled' or to walk and move like everyone else – something which leads to people downplaying the mobility they do have (Evans, 2013). The representation of disability as something which is either total or faked has real implications for the lives of disabled individuals.

Despite the obvious negative connotations of some of the language that is used around disability it is important not to forget that the intention behind words is significant – Francesca Martinez articulates this clearly when she says "Girls at my school used to run up to me and go 'You're a spastic!' And I doubt I would have felt much better had they gone 'You're differently abled'" (Are You Having A Laugh, 2010) – what is important here is the negative attitude she faced from other students, and the idea that she was somehow both other and inferior to the other girls in her school, not the exact phrasing that was used. Negative images in the media can be seen as contributing to those limiting attitudes.

The views and expectations that people have of disabled individuals will go beyond attitudes, and place restrictions on how disabled individuals are considered and treated by others, which in turn will put physical limits on the lives of disabled individuals. For example, when disabled individuals are not considered by society to be suitable parents, many changing tables for infants are not accessible (Nario-Redmond, 2010). A further example is the portrayal of individuals with intellectual disability discussed above, where the limited opportunities shown for individuals in film can restrict the lives of adults with intellectual disabilities (Renwick, Schormans, and Shore, 2014). By restricting our portrayals of disabled individuals, not only are a vulnerable group further emphasised as other, but life opportunities are closed off to them.

In contrast, there is a growing push by people involved within disability activism to represent disabled individuals fairly. This is mirrored by pushes by other marginalised

communities, and has been reflected in initiatives such as a diversified school curriculum and Black History Month. As disabled individuals often find that they grow up in a community where others do not share their experience (unlike many other identities, such as race), popular media is often the only source of information about the kinds of lives they can live. Scully (2008) speaks of choosing to consume all literature available about deafness, even though "the available fiction suggested my options were limited to becoming an art student before giving it all up for love of a hearing man… or a millworker and having hearing children who grew up to despise me". More recently, the Marvel comic book company created the character Blue Ear as a direct response to a mother contacting them to explain that her four year old son had chosen to stop wearing hearing aids because he felt isolated by doing so. By using an assistive device as a source of the hero's power (Blue Ear's hearing aids let him know when someone is in trouble), as well as acknowledging the use of hearing aids by Hawkeye, one of their key superheroes, they have used their role within popular culture to address issues of inclusion and allow for identification (Ellis, 2015). With disability a key part of identity, the provision of narratives can shape an individual's understanding of who they are and what they can do. This is backed up by Antle's research (2004) which shows that the self-worth of young disabled individuals is based on interaction with others and the ability to protect the self from negative narratives – meaning that these young people's views of themselves are based upon their ability to challenge dominant negative views of disability. Representing disabilities in a realistic way therefore is important not only for shaping the attitudes of society, but also for the self-worth of those who have disabilities.

Disability in the Public Gaze

One key element to understanding the representation of disability is the consideration of staring. As Garland-Thomson (2000b, p. 348) makes clear, "disabled people have variously been objects of awe, scorn, terror, delight, inspiration, pity, laughter and fascination – but we have always been stared at". Such staring remains a part of disabled lives today. Although staring is culturally proscribed, people often stare at those who are in some way unusual – a situation which can be uncomfortable both for starer and staree (Garland-Thomson, 2009). In addition, the history of the display of

disabled individuals appears as a catalogue of dehumanisation, with agency taken from those who are shown and held instead in the hands of major institutions and their non-disabled managers – be those managers showmen, doctors, or curators. In these cases, the disabled individual themselves has not had control over who is staring.

Staring is a part of life for many disabled individuals, as passers-by can find themselves transfixed by the unexpected. In a crowded public environment in which most people are strangers, people value privacy. There is a reluctance to look at each other, and people take "refuge in being invisible to each other", all wearing suits and trying to appear as normal as is possible so as not to draw the eye (Garland-Thomson, 2009, p. 35). Civil inattention is given to all those who pass without interesting us. Ellis (2017) examines the gaze theory, showing how certain groups are presented in a way which defines their social status – with the male gaze seen as sexualising and objectifying women's bodies. Whilst gazing implies a level of desire, staring instead implies a kind of surprise – a shock which we find ourselves drawn to despite an awareness of cultural restrictions on such an action.

There are many kinds of stare, all of which begin as an "urgent eye jerk of intense interest" (Garland-Thomson, 2009, p. 3) towards something which we find novel. Some stares are blank, others hostile, and others engaged, and which of these occurs can and often will shape the encounter that follows. Both the starer, and the individual who is stared at, can be left feeling uncomfortable by the encounter, as it is one that is socially controlled and forbidden. As such, it can be taken as rudeness or a challenge. However, as staring is driven by curiosity, it can enable new understandings to be formed, and to widen the starer's understanding of what it is to be human – "unpredictable things happen when people stare at other people" (ibid., p. 40). The male gaze and colonizing looks (in which people of different ethnic backgrounds are looked at as something exotic and strange) are seen as reinforcing the starer's status, by lowering the status of the object of their attention. Many of the stares faced by disabled individuals also lower their status. Stares aimed at disabled people can be accusative, or clinical, but they can also be baroque, fascinated by the difference. Garland-Thomson defines the baroque stare as a "giving over to the marvellous" (ibid., p. 50), as an individual is confounded and amazed by what they see – and it is these stares which she feels have the most possibility of creating an impact which lasts beyond the initial shock.

The stares disabled people face can devalue them for not fitting within expected cultural standards, and links to the history of disabled individuals as being "visually conspicuous, while being politically and socially erased" (Garland-Thomson, 2006. Disabled individuals can often find themselves the target of hate speech, especially when it can occur anonymously (Hadley, 2016; Burch, 2017), with the people who are spreading hate able to do so without looking the disabled person in the eye or having to answer in any way to their actions. Online, images of disabled people can be co-opted for a range of purposes, without the permission or awareness of the individual shown, as discussed above. Knowledge of such appropriation can cause fear and discomfort for disabled individuals, as is explored by Ellis (2017, p. 2) who explains how the "cultural construction of a 'dwarf' as an object of entertainment" has led to non-disabled individuals choosing to take images of people with dwarfism in public spaces. Such action marks individuals with dwarfism as other – as outside the construction of normality which is expected within public space. The individuality of the person with dwarfism is ignored, and instead they face ridicule, objectification and pathologisation. The pervasiveness of the camera phone means that disabled individuals are faced with the possibility of being recorded whenever they are out in public, with their image being consumed far outside of their own locus of control. As well as the initial stare, people with disabilities face the loss of power over their own image, as it is used to spread ideas, create humour (Hadley, 2016) and to generate fear (Biernoff, 2011).

Non-disabled people are used to images of disability being used in order to evoke emotion, to raise money for causes or to shock and horrify within film (Snyder and Mitchell, 2006). Such ways of looking affect how disabled people are viewed within society, with the simplified plot of such stories often reducing a character to their disability, and in doing so reinforcing the link between disability and stigma. In this way, disabled individuals find their own identity disavowed by those who choose to stare at them.

Garland-Thomson (2009) considers the ways that a disabled individual can gain control of the stare, at least if it is occurring within face-to-face interaction. Rather than focusing on the starer, she instead examines how the 'staree', the recipient of the stare, evaluates how they will respond – whether to look back or not, and if they will meet the

gaze, how to react. She offers alternatives to wilting under another's gaze, answering them back and in doing so reinforcing the staree's own humanity – considering for example Mary Duffy (an artist without arms), who uses her performance to state her body is effective, framing herself as the Venus de Milo and speaking her own words, re-narrating the audience's understanding of her image. In this way, Duffy is able to alter the audience's view of her, challenging their preconceived notions.

Garland-Thomson further emphasises how such work can enable an individual to build their interpersonal skills and develop a shared relationship, with the staree moving the starer beyond their initial surprise, towards normalising the disabled individual within their understanding of what a human can be – focusing particularly on artistic performances in which disabled individuals choose to display their difference and speak candidly with a non-disabled audience. She also uses the example of the Hensel twins. These two girls are conjoined, and while the initial portion of their life took place in private, at age six they emerged into the world with an article within *Life* magazine – "a carefully crafted invitation to stare" (2009, p. 180) which emphasised the ordinariness of the girls' lives. The only image which showed the girls being stared at is within a swimming lesson, and the girls stare back, as other students focus on their swimming – this shows how the girls have been accepted within their class, and are no longer seen as novel. Despite their young age, they are shown as being able to control the stares that they face, and in doing so are empowered.

Disability studies scholar Tom Shakespeare (2014) however questions whether this kind of understanding and evaluation of art performances will have much impact for those who live with stares every day, and may choose isolation to escape negative interaction. It is clear that for a disabled individual to gain control of the staring encounter, and to educate the starer, requires a lot of effort, energy and careful consideration of the situation that they are in. When someone is simply trying to continue with their own life, they may understandably be unwilling to engage with this additional labour, and indeed Garland-Thomson considers the use of cosmetic limbs in order to prevent staring. Despite a cosmetic hand's lack of functionality, preventing discomfort and being able to go about life unquestioned can be desirable. Here perhaps images and institutions such as museums have a role to play in countering the dehumanising attitudes that disabled individuals often find themselves faced with. If museums are able

to take part in the difficult work of challenging an individual's expectations, it may make life easier for disabled people within society as a whole.

Historic Displays of Disability

Over time, disability has been presented in a number of different ways. When attention first turns to the idea of displaying disability, the shadow of the freak show looms large – with Sandell (2007, p. 161) discovering that curators "invoked the freak show, and a desire to avoid freak show-style approaches" as a reason to avoid displaying the lives of people who had disability within their collections, not wishing to encourage gawping at people because of their differences. Concern over audience reactions can mean that curators are reluctant to show certain types of difference. However, a deeper consideration of the freak show itself offers one potential avenue of approach: despite the negative connotations of the word 'freak' today, freak studies scholars (Bogdan, 1990; Chemers, 2005) have argued that enfreakment was a socially constructed performance, based not on an inherent quality within the individual but on a manner of presentation. Bogdan argues, for example, that while Robert Wadlow was very tall, he wasn't a giant, as he did not cultivate the performance and persona necessary to be considered as such. Chemers argues that freakery consists of the "intentional performance of constructed abnormality as entertainment", exaggerating perceived deviance in order to gain money.

Framed as 'wonders' and 'marvels', the disabled performers within freak shows were seen not as objects of pity, but as entertainment. This sense of wonder can be seen within the carte de visites that many performers sold – these functioned as a visual resumé, highlighting their difference and advertising their performances (Garland-Thomson, 2000b). Within the freak show the difference of the individual is highlighted, but framed as something unique and valuable – at least within the context of the performance itself and the money it could create. However, such framing also set disabled people apart, implying that they were better off with their own kind rather than being included within the social environment of the world as a whole (Bogdan, 1990). Although the agency of individuals in freak shows is a more complex story than is often considered, this separation and exaggeration carried with it its own harms. This

particular approach tended to frame a disabled individual as a wonder, separate from the mass of humanity.

Freak shows faded from popularity in the early twentieth century, as they were targeted for outraging "social decency" (Church, 2011). This implied that such unusual bodies should be hidden, rather than displayed – that their presence in front of an audience was shocking and inappropriate. During this time there was a growth in medicalisation, and an emphasis on fixing rather than exaggerating any form of abnormality. Far from being an exotic spectacle, a disabled person was now presented in a way which showed them as "not a person but a diagnosis" (Bogdan, 1990, p. 277). Representations of disability moved from lurid and exaggerated paintings to clinical photographs with black squares across the eyes. Disabled people were now measured and recorded as the eugenics movement took off – responding to rapid industrialisation by attempting to remove any difference and a growing intolerance towards disability. Disabled people were scrutinised and examined, to see what was 'wrong' with them and how it could be repaired, and expertise in this matter was seen as lying solely within the hands of the medical professional – as can be seen in Garland-Thomson's (2009) account of David Roche's experience of examination in childhood, investigating his facial disfigurement. Here his body and face are exposed to doctors "as a pathological spectacle" (ibid., p. 183) facing diagnostic stares. For the Western medical professional, and Western society as a whole at this point in time, there was an emphasis on the "cure or kill approach" in which the disabled body was either to be normalised or eliminated (Garland-Thomson, 2000b, p. 355). For this purpose, medical information about disability was recorded, and invasive procedures carried out. These records led to mass sterilisation (with 63,000 individuals sterilised in the US by 1963), mass slaughter under the Nazi regime, and mass incarceration (Snyder and Mitchell, 2006). This shows disabled individuals approached as being medical specimens.

This mass incarceration removed disabled people from public view, placing them both in institutions and outside of mainstream education, working to hide them away from the rest of society. Initial attempts to cure soon turned into restrictions, which in turn allowed further research and increased the stigma of disability whilst also increasing the sense that disabled people were in some way exotic and unusual (Snyder and Mitchell, 2006), and as such an object worth looking at as they were uncommonly seen. Such

pathologisation of disability meant that any celebration of disability was viewed as "a perverse celebration of disease" (Chemers, 2005). At the same time, a growing awareness of disability rights meant that the use of an image of an identifiable disabled person could seem tasteless once removed from its medical surroundings (Biernoff, 2011; Chambers, 2010). As a result of this, disability representation is "not on the radar or subject to discussion in most institutions" (Sandell, 2019, p. 173), as doing so is seen as fraught with difficulty and the potential for offence, and disabled individuals are not considered as a group requiring representation – instead the focus is on enabling physical access (Majewski and Bunch, 1998). When disabled individuals are considered, the focus is often on ensuring they are able to enter buildings, rather than considering whether or not they will find representations of people like themselves within.

Individuals with disability have responded to this lack of representation in a number of ways – with Garland-Thomson (2000a; 2009) considering the work of several disabled artists who present their bodies on their own terms. Such performances are not without controversy, both within the disabled community and from outside. As discussed before, "Alison Lapper Pregnant", a sculpture of the artist Alison Lapper who was born without arms and with shortened legs, was displayed on the Fourth Plinth in London, and was criticised for celebrating "the distortion wrought by nature on a woman's body" (O'Neill, 2007), while every year newspapers debate about the performance of disabled individuals within pantomime (Ellis, 2017). Bogdan (1990) examines the case of Otis Jordan, a disabled man who performed as 'Otis the Frog Man' in the 1970s. Whilst he himself felt that the circus showing up was "the best thing that ever happened" (p. 280), he was temporarily put out of a job due to the complaints of another individual who felt his work was a symbol of the degradation of disabled people. Here, conflict arises as to what is an acceptable role for a disabled person within society, and who is best placed to make such judgements.

These four strands – the disabled person as wonder (within the freak show), as medical specimen, as something to be hidden (in institutions) or something to be shown on an individual's own terms – are still fundamental to disabled lives today, and the attitudes that disabled people face. Media and museums both focus on stories which draw attention, and difference does this (Mitchell and Snyder, 2000). The history of display

also affects how disabled bodies are framed, viewed and understood within today's society.

The history of the display of disability links to the images that are found within popular culture now. Images of disability are ubiquitous within society, allowing people to stare without risking censure. Garland-Thomson (2009, p. 58) examines the range of images out there, and chooses to fit them into four categories: "the wondrous, the sentimental, the exotic and the realistic", each of which is created in order to create a response in the non-disabled viewer and in doing so shapes public perception of disability. The wondrous image frames the disabled individual as above the viewer, doing something that the viewer could never do, a mode often criticised among disability rights activists as 'inspiration porn' (Hadley, 2016; Young, 2014). The sentimental frames the disabled person as below the viewer, helpless and in need of protection, as can be seen within traditional charity advertisements. The exotic frames them as apart from the viewer, as something alien, as shown in the carte de visites discussed above. The realistic portrayal minimises this difference and distance, aiming to regularise the disabled figure and show the impairment plainly and undramatically. The same individual could be presented in each of these ways, and yet the responses to them would be very different. This understanding of framing can help to shape considerations of staring within a museum context.

Disability in the Museum

So far, the focus on this chapter has been representations of disability within popular culture and the media, and the impact that these representations have had on the lives of disabled individuals. I am now moving on to considering the idea of disability as a topic to be approached by museums, and examining how this has been done effectively. In this section I will build on the work of the previous chapter, considering why museums are sites for discussion around disability, alongside exploring some of the concerns and difficulties that museums face when attempting to touch on such topics. I will also address the part that disabled people can play within the staffing of museums.

Disabled people have an important role to play in society's understanding of the world, both past and present, and this needs to be acknowledged. The concerns addressed above imply that such acknowledgement needs to be handled with care in order to prevent perpetuating negative images. The aim of this section is to consider how disabled individuals can be shown in museums with respect, acknowledging the realities of their lives and without provoking further stigma.

The fact that disability can be hard to present is not a reason to merely hide it away in the storerooms, but it does show that there are added layers of complexity to be untangled before fully meaningful and respectful portrayals can be created. This is an area that museums are currently examining in regard to many groups that have previously been underrepresented (Dodd et al., 2010). Some sites have already begun to engage in depth with this process, whilst others have further to go, and many continue to neglect the topic. However, positive examples suggest that people with disabilities can regain their part in history in a manner which treats them as individuals worthy of remembering, rather than objects to be met with a dehumanising stare.

The impact of staring is something that has been touched upon above, but is worth considering within a museum context. Museums exist as places where the attentive gaze is both encouraged and allowed (Sandell, 2007) – objects displayed within a museum are viewed as being worthy of attention. Recently, due to an increased awareness of the importance of representation, there has been a push within the museum sector to ensure that different groups are represented, in part to show value in a range of histories, and to emphasise the worth of various groups such as women, queer individuals and ethnic minorities. However, as has been discussed above, in relation to disability the history of display is far from simple. Society warns against staring at disability, whilst disabled people find that they are often the target of unwanted and unwelcome stares.

The desire to see yourself reflected in culture is a common one, although as Dodd et al.'s work (2006) shows, not all disabled people identify as being disabled. When the stereotypes faced by individuals with disabilities are so negative, it becomes more important to record and emphasise history "that presents disabled people and the Deaf community as active participants in history rather than passive victims of their impairments" (ibid., p. v). At the same time however, there is a concern that such

displays will merely replicate the freak show, displaying individuals for wide-eyed gawking. Rowan, a woman taking part in the 'Behind the Shadow of Merrick' project (Hevey, 2010b), says that as a child she was aware that the skeleton of Joseph Merrick, otherwise known as "the Elephant Man", was in a museum because of his difference. Further, she knew "my body was different and I had nightmares about the fact that doctors might put me in a museum, they might put me there before I was dead and that gave me really scary nightmares". Negative previous portrayals of disability in museums and the potential controversy that it can cause can lead to museums choosing not to display disability in case it invites "disrespectful and otherwise inappropriate ways of looking" (Sandell, 2007, p. 160). However, rather than using such reasons as an excuse to avoid potentially difficult topics, museums can instead engage with these difficulties, and use ideas such as Garland-Thomson's analysis of images to decide how to frame the stories that they wish to tell and to try and cultivate the results they wish within the viewer.

Research carried out by the Arts Council England (2019) showed that 4% of staff at the museums they examine identified as disabled, which is significantly lower than the 20% of working age adults in England who are disabled. Although some staff may have chosen not to disclose their disability, this underrepresentation can have an impact on how representative museums are. As will be discussed later in the thesis, initiatives are now being carried out in order to increase the number of disabled staff that can be found within institutions.

Another area that can be considered is evaluating the use that objects are being put to within the display. Thiemeyer (2015) offers an additional set of framing tools in his work on museum objects as work, specimen and witness, each of which carries with it a different set of values about what causes a particular object to appear 'museum-worthy'. Objects considered as works are judged on their aesthetic benefits, their rarity and uniqueness, along the value placed upon their creator – the most common form considered here is art, such as the Mona Lisa. Specimens are used to show taxonomies and examples, with focus being placed on the object as a representation of a broader category (such as a particular species of newt), with differential characteristics mattering only to show the difference between this object and other similar ones. Objects serve as witnesses when they are an authentic link to history, and are often

placed in context – their authenticity serves as testimony and enables them to tell a story and cause emotion. These three different understandings are used across museums, to help shape how objects are presented, and what is considered vital in the understanding of them.

Links can be drawn between Thiemeyer's work, and Garland-Thomson's (2009, p. 58) categories, along with the historic displays of disability which have been discussed above. The historic display of individuals in freak shows treated them as works under Thiemeyer's definition – objects to be looked at for their aesthetic benefits. This can also be seen within Garland-Thomson's framing of images that show disability as wondrous or exotic – all of these characteristics are focused on how something looks, what marks it out as different and as worthy of looking at.

The medicalised view of disability, in which it was hidden away from view and treated as something that needed to be cured, can be seen to parallel Thiemeyer's idea of the specimen – individuals are valued not for themselves, but as an example of the group to which they belong – for example, amputees or those with mental illnesses. The focus here was placed on classifying disabled people, who were viewed as lesser and in need of help – tying into Garland-Thomson's discussion of sentimental photography often used in charity campaigns.

Finally, the idea of using objects as witnesses, to draw on lived experience and their link to the events, matches well with Garland-Thomson's idea of realistic portrayals of disability. It also works with the current push by the Disability Rights Movement (an ongoing social movement aiming to support the rights and opportunities of disabled individuals) to encourage disabled individuals to be presented in their own words, drawing on their own experiences to explain what their lives are like to live.

However, such a grouping is greatly over-simplified, especially in the application of Thiemeyer's categories of work and witness – I have here considered how the disabled body was used at the time, rather than how it would be understood now. Whilst the value of the individuals in freak shows was in their uniqueness, many objects that survive from that time instead would fall into the witness category as it would provide information of the lived experience of those who spent time within these displays.

Similarly, the idea of an object as witness could speak to any of the other categories. Despite this oversimplification, such a taxonomy begins to show one method through which disabled individuals can be presented respectfully – with objects from their lives, and their own words, being used to give a realistic understanding of the life that they lived.

An example of how this can be achieved would be the 2005 Smithsonian exhibition *Whatever happened to Polio* (Sandell, 2007, p. 162), in which an effort was made to include the experiences of those who had polio, including personal images of "people with polio in everyday situations, going to parties and picnics, getting married and playing with their children". In a direct response to more medicalised imagery that was commonly shown around polio patients, this exhibit tried to provide a wider understanding. These photographs serve as Thiemeyer's witnesses, explaining what life was like for those who lived it, whilst also showing Garland-Thomson's idea of a realistic portrayal, going beyond a medical view and examining the life of the person as a whole.

Using a disabled individual's own words in the creation of a story about their life helps prevent a return to stereotype, especially when accompanied by other elements such as those just discussed, which serve to humanise the individuals shown. Several projects have been carried out which encourage the audience to look at disabled people in a respectful and considered way. Chimirri-Russell (2010, p. 169) examines a retrospective on the cartoonist Everett Soop's life, in which quotes from Soop himself were placed centrally within the exhibit to meet the family's desire to show him as a "brilliant, many-faceted and flawed human being who happened to have a disability". Here, whilst Soop's disability was acknowledged, and his wheelchair displayed, it was his activism and work that was the focus. This encouraged the audience to reconsider their expectations of what a disabled individual could achieve, and showed his identity beyond the existence of his disability, whilst at the same time acknowledging that he lived his life as a disabled man.

In another project, the story of Joseph Merrick was retold in a short film which featured disabled individuals interacting with key objects from his life, and linking the objects to their own experiences (Hevey, 2010a). In this way, Merrick's humanity and lived

experience was shown in a way that inspired empathy rather than fear. By showing Merrick in his own words and the words of individuals like him, he is humanised. By drawing these links and allowing disabled individuals to speak for themselves, preconceptions can be challenged and the power of the stare utilised for good.

Whilst both of these examples have focused on objects, exhibitions filled with images of disability can also be created in a way that frames them positively. Douglas Auld's 'State of Grace' (2004) paintings are a series of images of burn survivors. Inspired by a negative response the artist had to a burn survivor when he was younger, these portraits imbue the subject with a sense of respect and commemoration, inviting stares but also admiration (Garland-Thomson, 2009). Similarly, Lehrer's portraits of disabled individuals use traditional symbolism to convey high status and symbolic capital on the individual depicted. This encourages a close reading of the image, and indicates that the individual portrayed is someone worthy of having a portrait painted (Garland-Thomson, 2010). Whilst people may still have a negative response to these images, by portraying them in a positive and respectful light the artwork frames the conversation, and shapes the audience's likely response.

Unlike the cult film, or the fantasy story in which the inclusion of the disabled body is often used in order to entertain, emphasising the "subversive taboo qualities" of the people depicted (Church, 2006), museums are commonly viewed as a site of high culture and of value. By a museum choosing to depict disabled individuals, especially if such depiction is carried out with respect and consideration, value is bestowed. Museums have increasingly been seen as appropriate sites for human rights work as shown in the last chapter, and can ensure "equality, dignity and respect" (Sandell, 2019 p. 169) for disabled individuals. Rather than encouraging gawping, the display of disability within the museum can increase understanding and alter how people think and talk about difference.

Alongside concerns about staring, other interlinked problems arise in respect to the display of disability (Sandell, 2007). The three areas which overlap are questions of visibility, issues about outing individuals, and issues with naming. Disability may be a part of someone's identity, but it is not the entirety of their identity, as was shown in Chimirri-Russell's work above. Choosing to focus on that aspect of a person, making it

visible, may seem tokenistic or inappropriate – if an artist has a disability, but does not consider themselves disabled and does not tackle disability-related issues in their art, then saying that they are disabled could be interpreted as being reductive. This is particularly true of individuals in the past where the evidence for their disability is unclear, or for individuals who deliberately chose to hide their disability.

If a museum chooses to label someone as disabled when the person themselves rejects that label, difficulties can arise, as will be seen later within NDACA's work. The correct response to such circumstances will need to be considered on a case by case basis – for example, President Roosevelt tried throughout his life to keep his disability from the public eye, as he believed that it would affect his political career. However, depictions of him using a wheelchair are now common – by revealing his disability, it is possible to challenge views about the capacity of disabled individuals (Sandell, 2007). Similarly to revealing the LGBT+ identity of a historical figure, the decision as to whether or not to identify someone as disabled will need to be made carefully – considering both the feelings of the individual and living relatives, and the potential impact on the audience's views, and weighing up whether the disclosure would be suitable. Choosing not to reveal someone's disability can be interpreted as saying that the disability is something that should remain hidden, or can be viewed as shameful, further reinforcing negative attitudes and stereotypes.

In order to encourage respectful looking, the identity of the person on display should be respected. One way of doing this is to use the idea of realistic portrayal, as discussed by Garland-Thomson (2009). Another method would be to ensure the real name of the person is included, as a lack of names is felt to "inhibit visitors' capacities to make personal connections" (Sandell, 2007, p. 167). However, use of an individual's name is not always possible. Medical images often do not have the name of their subject recorded, permission may not be gained, and there are legal rules around the anonymity of patients. Such restrictions can dehumanise the individual portrayed. An extreme example of this is considered by Biernoff (2011, p. 325), when she considers the way that case photographs from injured World War One soldiers have been reworked to create "subhuman monstrosities" within the videogame *Bioshock* (2007). Shocking images without a name can encourage the kind of staring linked to the freak show – or can even cause repulsion among viewers to the extent that they turn away, and rather

than seeing the disabled individual as human, they view them as irrevocably other. Here work such as Hevey's (2010a) can enable the voices of those who have shared these experiences, and so create a nuanced portrayal even for images in which an individual's identity has been taken away and their voice lost.

Considering all of these aspects, there are still a number of different methods of presentation and a range of focuses which can be used when examining the display of stories related to disabled people, and these different frames will alter how the audience looks. That in turn will impact the kind of stare which is directed towards the object or image, and the individual that it represents. Depending on the type of museum that is considered, different approaches will be taken. An example of this is how the Science Museum Group have used prosthetics to tell "clinical, technical and personal stories" (Goggins, Philipson and Alberti, 2017). By working with both prosthetic users and designers, they have been able to balance narratives of use with an explanation of the techniques used to create them. Some of the exhibitions that they have held have focused on the techniques and technology used within artificial limbs, whilst others have been focused on the individual user. Although at points these displays have relied on the medical model, showing prosthetic limbs as "technical answers to practical and social need", the focus has been on human problems, and the "relationship between user and maker" (ibid.). By careful framing, the museum was able to balance the desires of those involved in the creation of the limbs, and those who used them – including those who found them inappropriate: stating that "many of the children born without arms rejected prostheses and became skilled at using their feet, though Edinburgh had a comparatively low rejection rate" (ibid.). This both praises the engineers involved and reflects the lived experience of prosthetic users. Both of these groups are users of the museums, and part of the community, and both views deserve to be treated with respect. Enabling these complex and multi-faceted interpretations within the museum setting challenges the simplified stereotypes that the museum visitor may have arrived with.

Conclusion

Whilst the history of displaying disability involves a number of ideas that museums now wish to distance themselves from, this is not sufficient reason for them to avoid showing information and artefacts linked to the lives of disabled people, but rather a cause for them to handle such display with respect and care. Museums can impact everyday struggles and create "more equitable and just ways of seeing" (Sandell, 2019, p. 169). This can be seen by the work of Dodd et al. (2010), which evaluated how visitors responded to museum projects which examined disability. Their research discovered that museums can "offer visitors credible and permissible ways of understanding disability" (ibid., p.103), introducing concepts such as the social model to visitors, as well as giving disabled people's voices the authority that museums hold. Representation is important, and museums are able to use their position to challenge harmful stereotypes and present positive images.

Not all visitors will come to a museum with the same previously lived experience, or the same prior knowledge of disability. Whilst ideas such as the social model are widely accepted within the disabled community, they are not known by everyone. Museums must reach out towards their audiences, and help visitors challenge preconceptions that they might already hold – which can only be achieved if the museum itself already questions stereotypes rather than merely reproducing them (Sandell, 2007). Museums can also work with disability rights groups, and use the lived experience of disabled individuals to shape their work – something which was done to great effect by Hevey (2010a) in the creation of his film examining the life of Joseph Merrick.

More widely there is a push to increase the presence of disabled individuals within the media (Ellis, 2015), and to ensure that it is done in a way that is respectful rather than simply promoting gawping. Here, Garland-Thomson's article (2000b, p. 339) and the framework she creates for evaluating images of difference – separating images into "the wondrous, the sentimental, the exotic and the realistic" – can help sites consider the message they want to share, as does the work carried out on the ways that objects are used (Thiemeyer, 2015). Although one of these studies is over two decades old, the framework it sets out is still of use to us. By taking these ideas, and foregrounding the work and words of disabled individuals, it seems that a more equitable form of display

can be achieved. Simply because displaying difference and controlling the kind of stares that will be received is difficult, this does not mean it is a topic that should be avoided. Instead, the potential influence is great enough that museums and other sites should try to reach out in a way that includes disabled individuals, increasing awareness and understanding of the lives of a section of their own audience. How such objects, images and people are framed and explained is central to ensuring that the responses which are received match the considerations the museum wishes to achieve.

Looking at the literature, I have been able to discover the potential harmful impact of certain forms of representation, and the hope that other forms of display and interpretation provide. Although some representations of disability have been negative, there are others that open up the possibility of empathy, inclusion, dignity and respect. It is these examples that I shall explore as I continue with my thesis.

Chapter Four – Research Methodology

Introduction

This chapter examines the approach that I have taken towards the research detailed within this thesis, and the philosophies and principles which have underwritten it throughout. It explains both my primary and sub-research questions, and then explores the methods I have chosen to use. Beginning with my decision to use qualitative research, the chapter then narrows its focus to examine case studies and my own position as a researcher. My attention then concentrates further on considering the types of data sources which were used, and how they were analysed. Having set out the reasoning for selecting my case studies and explained how I was able to make use of this within the thesis, I finally consider the practical and ethical issues inherent within such an emotive and at times difficult topic.

This chapter therefore establishes the methodology behind my research, from its broadest scope down to the practicalities and ethics that arise, and explains my reasoning. Therefore, I will be in a position to proceed to the case studies themselves in the following chapter.

Primary Research Question

The overarching questions which drove this research were:

> How are disabled people and stories of disability represented in exhibitions and displays within UK museums?
>
> > and
>
> Which factors, aims and concerns shape these narratives?

The research aimed both to uncover current representation, and to understand the reasoning behind such work. I also hoped to consider the implications and impact that these representations have had on contemporary debates around disability and difference. In order to fully investigate this, a number of sub-research questions were created, which will be considered in more detail below. The sub-research questions

could be broken down into two main groups – one concerned with the narratives and objects shown within the collection and their presentation; the other focused upon staff attitudes and the role of museum representation, interlinking with wider debates within museum studies, disability studies, and society as a whole.

Sub-questions considering representation within museums:

- How are objects linked to disability presented within museum displays and exhibitions?
- What meanings and messages pertaining to disability can be discerned within museum displays, and how do these relate to narratives of disability that circulate in the broader mediascape?
- How has this presentation changed over time, and what factors have shaped this?

These questions examine what items and narratives museums display which are connected to disability, and also evaluate how museums present these objects and information to the public in both physical and virtual settings.

Sub-questions considering views, aims and impacts beyond the museum:

- How do museum staff perceive disability as a topic for presentation?
- What aims lie behind the inclusion of disability-related material in museum displays?
- What challenges do exhibition-makers perceive in presenting disability-themed material, and which strategies are used to address these?

These questions explore the attitudes which shape the presentation discussed and consider the impact of these attitudes on contemporary debates around disability and about the purpose of a museum.

I will examine each of these questions in more detail later in the chapter.

Why Qualitative Research?

From the beginning, it was clear to me that I would benefit from approaching this topic using qualitative methods. Creswell (2003, p. 18) defines a qualitative approach as one where

> "…the inquirer often makes knowledge claims based primarily on constructivist perspectives… or advocacy/participatory perspectives… or both. It also uses strategies of inquiry such as narratives, phenomenologies, ethnographies, grounded theory studies or case studies. The researcher collects open-ended, emerging data, with the primary intent of developing themes from the data."

Unlike quantitative data, which is measurable and communicable by the use of numbers within a fixed system, qualitative data is more open-ended. It is based on an understanding of the world as socially constructed, with a focus on participant meanings and interpretations (Creswell, 2003; Denscombe, 2007).

Qualitative research can be used within the social sciences to develop thick descriptions (Woodside, 2010). Thick descriptions are multi-layered and complex accounts of what occurs, including the context around the studied phenomena and considering subjective explanations and meanings. Whilst such thick descriptions are less generalisable than data gained from quantitative study, they are better equipped to handle the complexity of real-world issues, illuminating the subjective and multiple meanings which individuals attach to certain concepts and actions (Creswell, 2003).

As the aim of my research was not just to develop a numerical understanding of what museums contained, but to analyse the narratives that they presented and the meanings attached to those narratives, I decided to make full use of qualitative methods.

Why Case Studies?

Having decided to use qualitative methods as the starting point of my research, a decision had to be reached as to which form of this would be most suitable for the study I wished to undertake. I chose to make use of the case study. Denscombe (2007, p. 36) defines the case study as one which aims to "illuminate the general by looking at the

particular". A case study is an in-depth account of an example, or a few examples, of real-world phenomena. This is achieved using multiple sources of data, in order to build multiple perspectives and so draw out the subtleties and intricacies which govern the phenomena. It is research undertaken at a small scale – looking at a few examples, rather than the thousands or tens of thousands which might be used for a quantitative survey – as the aim is to achieve depth of understanding not breadth.

Denscombe (2007, p. 55) provides the following table explaining the varied uses to which case studies can be applied:

Discovery Led	
Description	Describes what is happening in a case study setting (e.g. events, processes and relationships)
Exploration	Explores the key issues affecting those in a case study setting (e.g. problems and opportunities)
Comparison	Compares settings to learn about the similarities and differences between them
Theory Led	
Explanation	Explains the causes of events, processes, or relationships within a setting
Illustration	Uses a case study as an illustration of how a particular theory applies in a real life setting
Experiment	Uses a case study as a test bed for experimenting with changes to specific factors or variables

This particular study was primarily concerned with the aspects identified as discovery led: describing and comparing the different cases, and exploring the issues which affected these studies, then using these discoveries to develop theories. However, such exploration in turn led to a degree of explanation.

The use of the case study therefore was an iterative process, as shown by Rule and John (2015, p. 10):

Theory of Distributed Leadership

Application of theory

Multiple cases

Across-case analysis and interpretation of data

Revision and development of theory
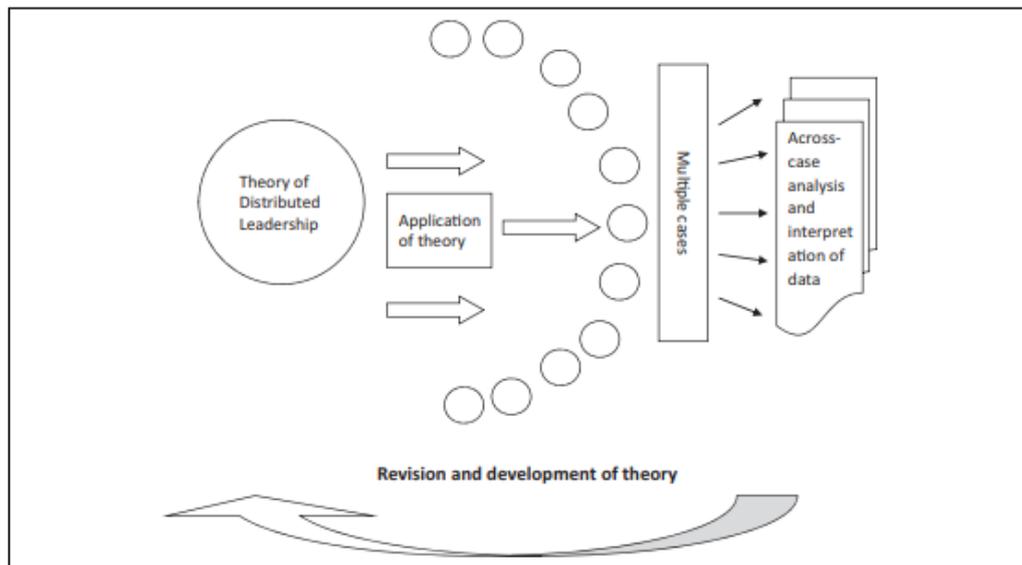
The application of theory – in particular looking at topics through the social model lens – shaped understanding and analysis of the cases, but this understanding and analysis in turn shaped the theory which drove my work – going beyond the social model in order to consider the range of narratives shaping contemporary debates around disability equality.

Critiques of the Case Study as a Method:

There are several critiques of the use of the case study as a method (Denscombe, 2007), which I have tried to address here.

- Unsuitability of information gained from case studies to generalise: Whilst each case is unique in some respects, it is also an example "of a broader class of things" (Denscombe, 2007, p. 60) – if enough information is provided, the reader will be able to make an informed judgement as to the applicability of research to other cases. The ability to triangulate between different methods not only increases the depth of information which can be considered, but also enables different methods and data sources to corroborate each other. Furthermore, as I looked at several varied cases and contextual examples (as

discussed below), patterns which emerged from all of them seem likely to be generalisable to other sites, at least to some degree.

- Creation of 'soft data': A critique often applied to qualitative research as a whole is that it only provides data which is full of interpretations, contradictions and uncertainties. This however can be regarded not as a weakness but a strength – the real world does not come neatly parcelled out in a numerical way, but is instead socially constructed by the messy interactions between individuals, institutions and societies. Qualitative research and case studies view social phenomena holistically (Creswell, 2003) which enables a deeper, more complex and more nuanced understanding to be reached by regarding the situation as a whole, rather than as separate fragments.

- Difficulties in deciding on the boundaries of a case: This particular objection posed little difficulty in this study, as the focus was always on either a particular museum or a particular exhibit which centred on disability, and its attached external communications – its website and publicity material. This meant the boundaries of each case were clearly defined.

- Access to the case or cases: The selection of my cases was to some extent shaped by access, as will be discussed below. Whilst this was not a prime consideration when deciding on sites to examine, it helped to shape the scope of the project, leading to my focusing on museums within the UK. This geographical focus also enabled more relevant comparisons between the considered sites, meaning that findings would be more generalisable within one country and it was likely that at least some of the issues faced would be similar between cases as they operated within the same framework.

Despite these potential issues I found that the case study was a suitable way to approach my topic, as it allowed for the development of the rich and intricate understandings that were the goal of this project. Also, the use of multiple case studies enabled some of these objections to be avoided or minimised, as comparison could be drawn across and within sites. Such triangulation helped increase the reliability of data and provided the possibility of reaching generalisations which nevertheless remain bounded by context.

Values

Whilst my goal within this research was to undertake case studies focusing on exhibitions, websites and interviews with relevant staff members, my work was shaped by a number of different methodologies and a range of values. Key to my research were the ideas of emancipatory research, values-driven research, social justice, transformative research, and Snyder and Mitchell's (2006) work on the cultural locations of disability.

Disabled people have previously often been excluded from the research process. It is something which has been done to them, rather than with or for them. The researcher has been the one who has controlled the research and held knowledge, and who has benefitted from the involvement. The disabled person has merely been a research object, a fact explored in Snyder and Mitchell's *Cultural Locations of Disability* (2006). This research shaped my own as it demonstrated how the portrayal of disability and of disabled narratives can affect both the self-view of the disabled individual and their treatment by society. When disabled individuals have often been closed out from mainstream culture and participation, their representation and inclusion within sites such as museums has the potential to either challenge or continue this process. Emancipatory research can help prevent museums from further isolating disabled individuals by including and respecting their views and voices – a process detailed in more depth within Chapter Six.

Following on from the ongoing work of the Disability Rights Movement, which aims to support the rights of those with disabilities, there has been a growing campaign to enable disabled people to participate meaningfully in debate and discussion about their lives. "Nothing about us without us" has become a key message in the Disability Rights Movement – disabled individuals demand to be not just the passive topic of research, but co-researchers whose knowledge is respected and who benefit from their participation in the process. This has been seen within the literature analysis. The focus of such emancipatory research is often on the lived experience of disabled individuals, and on building a meaningful relationship between the researcher and the one that is researched. It aims to remove barriers, with Oliver (1992) picking out the key principles

of reciprocity, empowerment and mutual benefit, gained via a transformational dialogue. Here, the location of power is shifted, and disabled individuals are viewed as researcher collaborators, working with the researcher for joint ownership of outcomes. It is a reflective process, willing to adapt to meet the needs of participants, and it accepts that it is not neutral but is instead to a degree political as it supports a disadvantaged group. This approach fitted well with the research that I was doing, as it mirrored steps that are being undertaken by museums themselves, as will be shown later.

This emancipatory model shaped my understanding of the goals of disabled individuals participating in research, and also helped me to appreciate the work that museums are doing within any projects they undertake that reach out to the disabled community. In addition, it guided me towards the other methodologies which I discuss below.

As Creswell (2003) emphasises, a researcher is not neutral, but arrives with a range of values and beliefs which affect them and influence how they approach their research. My own position is explored more below, but as with any researcher I came to this project with my own values. I am committed to the idea that museums are not neutral (Sandell, 2007) – if they present both sides of an argument on an issue such as global warming or gay rights, they are sending out as clear a message as if they only showed one perspective. I approached this research using the social model of disability, but also with the belief that people should be able to see themselves and their histories presented in museums. This belief was at the forefront of my mind throughout my research. Linked to this is the idea of transformative research – the idea that research should have an impact and cause some form of change rather than simply gathering facts that will not be used. This meant that I set out to find out what was being presented in order to highlight current best practice and enable others to move towards and indeed beyond this point. I was mindful throughout the project that I was undertaking this research for a purpose, with the hope of gaining knowledge that could be used for wider benefit. This purpose also shapes my plans following the completion of my thesis, as I intend to continue this work and bring forwards further stories around disability and sexuality.

The issue of representation reaches beyond museums and into the broader sphere of public life. This drove me both to examining how media presents disability and also to

considering the human rights implications of disability, both of which are included within the literature review. The UN Convention on Rights of Persons with Disabilities (2007) says that an impairment "should not diminish human dignity or access to opportunity" – it sets out inclusion as not merely benevolence but a right (Ouellete, 2016). If this is accepted, then not representing a group and their experiences, and consequently not showing them as worthy of respect, can be seen as depriving them of an opportunity and therefore taking away their human rights. This is because cultural representations are able to both create and reflect ways of "seeing, thinking and talking about disability", and so shape the opportunities available to disabled people (Sandell and Dodd, 2010, p. 3). This link to human rights emphasises the potential importance of ensuring people can see themselves represented, especially alongside the work of Snyder and Mitchell (2006), Oliver (2010) and Gartner and Joe (1987), among others, which show the real-world impact of media portrayals on the attitudes of society and of individuals towards disability.

Throughout this project, my research was driven by a desire to foreground the experiences of those with disabilities and to discover and share current best practice of disability representation. My goal was to evaluate and analyse representation, and to see how current work could shape future displays. I wanted my research to have real-world impact and to cause change, to be action-led and lead to positive outcomes for the representation of disabled individuals (Kitchin, 2000). These values helped me to form an understanding of what best practice might look like and gave me a starting point from which to begin my evaluation.

Positioning the Researcher

I approached this project with a strong interest in disability rights, and in the rights of minority groups more generally. As a queer autistic woman, who has used a laptop throughout her formal education due to dyspraxia, I have been drawn to 'hidden' histories – stories beyond the mainstream flow of history, where people like myself stand in the shadows. My own reliance on a disability aid, in the form of technology, made me curious about what traces disability has left in different societies throughout history. This led to my creation of a Twitter account (@Our_Objects) which I set up in

July 2016, and on which I have daily posted a museum object related to disability, sharing information about the range of material culture that has been linked to disabled lives (Our_Objects, 2020).

My identity as a disabled individual is particularly significant, given the way that disabled people have often found themselves excluded from the research process, as previously discussed. My identity had a role to play in drawing me towards this topic initially; however I was careful to approach my research from an academic rather than emotional standpoint.

Creswell (2003) says that as qualitative research is interpretive and personal, viewing social phenomena holistically, then inquirers need to "explicitly identify their biases, values and personal interests about their research topic and process" (p. 183). These biases shape the researcher's approach to their work, but can be overcome to some extent if they are acknowledged. Denscombe (2007) supports this, emphasising that researchers need to be honest about how their agenda has been shaped by experience, and in doing so approach topics reflexively and with an open mind (p. 301), as making sense of what is seen "relies on what the researcher already knows and already believes" (p. 88). Maintaining an open and reflexive mind is what I have attempted to do within this study, considering the point from which I am starting so that I am able to challenge and assess the biases that I bring to my research, whilst also acknowledging where such views (such as the importance of the social model) are reflected within the wider disability community.

Research does not just happen: it is carried out by an individual or a group of individuals, towards a set end. The goals and beliefs of these individuals therefore influence the final result, and the issues that they feel are worthy of examination. Throughout a research project, the act of being a researcher is itself a performance (Walshaw, 2008, p. 322) which develops a kind of self – and therefore reflection is vital. That is because this reflection helps reveal who the researcher is, and to ensure that what is being heard matches what is being said.

Reflexivity allows for self-knowledge and sensitivity (Berger, 2015, p. 220), helping the researcher to consider their own role and the biases that they have brought to their

research. By acknowledging their own reactions and maintaining an awareness of themselves, researchers are able to pick out additional strands from their research, and to show compassion. However, reflexivity still happens though the eyes of a researcher and there is an unavoidable mis-recognition "between how one party perceives itself and how the other party perceives it" (Walshaw, 2008, p. 334) – even when being reflexive in research, it is impossible for a researcher to prevent their own identity intruding on their research, particularly if it is pertinent to the research topic as is the case here.

Berger (2015) examines the role of reflexivity when a researcher shares experience with those being researched. This was to some extent the situation I was in: whilst I was not working as a museum professional during my research, I have previously volunteered at museums; I am also a disabled person, meaning that I understand some of the fundamental issues of living with an impairment, alongside the importance of including the voices of disabled individuals within my work (Kitchin, 2000). In addition, I had researched this topic for a year prior to beginning this thesis, and therefore was familiar with the kinds of objects and stories museums often held in relation to disabled lives.

The advantages that Berger emphasises for researchers in this situation are the head start in understanding what is being said and in picking out nuance (2015, p. 223). However, she also discovered several risks since researchers impose their own values and biases. Being aware of this meant that throughout my research I could compare my understanding with what the participants were trying to convey by using member-checking and in doing so aim to ensure that the data I gathered was as far as possible not negatively affected by my biases.

Data Sources

Once case studies were selected as the methodology for carrying out my research, further consideration needed to be given as to the kinds of data source that would be looked at for each case study site. After that, I would need to consider how these data sources could be brought together in order to construct a cohesive examination and explanation of the state of, and motivations for, current disability representation.

The methods I selected were interviews with museum staff who were involved in the creation of these exhibitions, as well as analysis of both the exhibition (including elements such as audio guides) and external communications. These methods were to be carried out at all three of my case study sites. In addition, previous and upcoming exhibitions within the institutions in question would be analysed where appropriate. The contextual examples (discussed in Chapter Five) would not necessarily involve all of these methods, instead being used to highlight significant elements to compare or contrast with the case studies.

These methods were selected in order to both examine the content of the exhibitions, and to consider the motivation driving the individuals responsible for the creation of the cases in question. The hope was that the exhibitions would be able to reflect the ideas that the creators and designers mentioned, and that therefore a link could be traced between the end product and the intentions behind it.

Having explained which methods I used, I will briefly lay out what I mean by each term so that the link between method and research questions is clear.

Interviews go beyond merely being conversations: the interviewer sets the agenda, and the interviewee must give their consent. They are useful as they enable insight into "people's opinions, feelings, emotions and experiences" (Denscombe, 2007, p. 174). In addition, they "allow respondents to express and contextualise their true feelings" (Kitchin, 2000, p. 43) rather than forcing them to simplify their responses, as can happen in questionnaires. Furthermore, they enable the detailed examination of sensitive issues and can reveal privileged information that is not otherwise available, although this information is often in the form of a "tidied up" account (Macdonald, 2001, p. 86) as the interviewee tries to fit their experience into clear and unified answers. This is particularly the case when questions remain fixed, rather than changing to adjust to the discussion which is being held.

This project made use of semi-structured interviews, in which there was a list of questions to be discussed (see Appendix A), but these questions were open-ended, enabling deeper exploration of any interesting points raised. The interviews I carried out

were all on a one-to-one basis, which meant that opinions and views were clearly traceable to their source. However, the interviewer's identity also affects the response of the interviewee (Denscombe, 2007, p. 184) – this is something which is uncontrollable. Despite this, I tried to put my participants at ease, and gave them some control of the situation by allowing them to ask any questions that they had and by offering them the chance to member-check the interview transcripts.

Whilst it is possible that an interviewee is lying (be it intentionally or not), or merely telling the interviewer what they believe the interviewer wishes to hear, interviews enable the provision of deep information and insights (Denscombe, 2007, p. 202) and allow for alterations to handle issues and interesting topics that arise during the discussion. Interviews were the main method used to gain an understanding of the participants' own motivations and goals, as it enabled them to express these within their own words.

Exhibition analysis involves the analysis of various elements of an exhibition: the panel text, the layout, the objects included, and the information provided about them. Exhibitions are able to use "space, setting and the active engagement of the visitor in the creation of more meaningful and memorable encounters with museum objects" (Hale and Back, 2018, p. 340). Considering how exhibitions are laid out can help to understand the visitor's experience, as museums serve as a "fully immersive medium of spatial and bodily communication" (ibid., p. 348). The information provided on text panels is important, but so is the accessibility of the site, and the layout and presence of hands-on objects can help with this. The space within museums can form a "vital, valued and socially impactful space" (MacLeod, 2018, p. 14), but only when considering how the spaces can be used in a meaningful way, which takes into account users and their lives (p. 25). Analysing an exhibition involves considering both what is displayed and how it is shown within the space available, with the museum conveying messages – both intentional and not – through all of these elements.

Recent research on exhibition design has emphasised the importance of co-curation and multisensory exhibitions in order to ensure accessibility (MacLeod, Hale, Austin and Ho, 2018, p. 352). By reflecting on how the sites were able to make use of these elements, a greater understanding of the messages which sites share can be seen –

whether the museums are democratising or alienating their visitors (p. 353). The co-curation of elements of the exhibition is discussed in depth in Chapter Six, whilst Chapter Five considers the multisensory elements of the exhibitions.

The analysis of external communications highlighted similar details to the exhibition analysis, considering different ways that the information had been made accessible and inclusive. This is set out in Chapter Five, and examines how the sites were reaching out to or else excluding disabled potential visitors.

Once I had selected the methods for my research, I ensured that they would enable me to answer the sub-questions I wished to ask. This work is set out in the next section.

Research Sub-Questions

The tables below return to the research sub-questions discussed earlier in this chapter. For each sub-question which data sources and methods would be of most use in further research are examined, and a justification is given as to why particular methods have been selected (Mason, 2018).

Questions considering representation within museums:

Research Sub-Questions	Data Sources and Methods	Justification
How are objects linked to disability shown within museum displays and exhibitions?	Analysis of exhibits, websites, and records of past exhibits	Examines how objects/narratives linked with disability are framed by the museum.
What meanings and messages pertaining to disability can be discerned within museum displays, and how do these relate to narratives of disability that circulate in the broader mediascape?	Analysis of exhibits and interviews with staff members	Interviews will reveal narratives museums are trying to show and observation will examine how successful this has been, so that comparison can be drawn.

How has this presentation changed over time, and what factors have shaped this?	Analysis of exhibits and past exhibits, interviews with staff members	These methods will allow comparison between past exhibits and current ones, revealing the change over time, whilst speaking to those involved will explain what has shaped these decisions.

Questions considering views and impact beyond the museum:

Research Sub-Questions	Data Sources and Methods	Justification
How do museum staff perceive disability as a topic for presentation?	Interviews with staff, analysis of exhibitions and websites	By speaking to staff, they can explain their motivations, whilst an analysis of exhibits will reveal the extent to which these claimed motivations are reflected in the exhibits themselves.
What aims lie behind the inclusion of disability-related material in museum displays?	Interviews with members of staff, examination of exhibits	Interviews will show staff attitude and aims, whilst observation of the exhibits will show the terminology and explanations the museum presents to its audience.
What challenges do exhibition-makers perceive in presenting disability-themed material, and what strategies are used to address these?	Interviews with members of staff	Interviews enable museum staff to explain the challenges that they faced and how they were able to address these, as well as revealing changes that occurred during the design process.

A combination of methods was therefore used in the collection and gathering of data. Using such mixed methods allows the possibility of triangulation (Creswell 2003), enabling results to have increased validity – concepts picked out in one area can be traced through others, to develop a fuller and deeper understanding. Once such data has been collated it becomes necessary to analyse it, in order to reveal messages and patterns that exist within and between such cases.

Analysis of Data

Once data had been gathered, and indeed during the data gathering process, it was necessary to analyse it in order to pick out key themes and to generate understandings. Approaching each site with standard interview questions and analysing the same features in exhibitions and websites allowed there to be a degree of similarity between potential results, enabling comparison, although the variation within the sites chosen meant that not all questions were relevant at all sites and for all interviewees. I used semi-structured interviews, allowing for interesting threads which developed during the discussion to be explored in more detail, rather than rigidly sticking to the same fixed approach each time.

As discussed above, a mixed methods approach was used to gather data, allowing for triangulation but complicating the drawing of comparisons. Enabling a rich description of the sites and information (Creswell, 2003) added to the depth of what could be discovered, but to enable an overall narrative to emerge the data needed to be broken down and reshaped by coding.

Denscombe (2007) sets out a number of stages for this: preparation, initial exploration, analysis of the data, representation and display, and validation of the data. All analysis and conclusions need to be grounded – that is to say that they should emerge "from a careful and meticulous reading of the data" (p .287) rather than from the researcher's preconceptions. This in turn means that data analysis is an iterative process. Having first familiarised themselves with the data, the researcher can code it, picking out what is being said at any particular time and linking it to key emergent themes.

Once this task is complete, the codes can be categorised and the relationships between them worked out as the number of codes is reduced, related concepts merged, and certain ideas prioritised. Comparisons can be made between sites after the discovery of key concepts, and the overall conclusions can be linked back to the data that was gathered. This validity can be ensured through having an audit trail, which enables decisions to be followed from conception to conclusion. Wrona and Gunnesch (2016) argue that this empirical research enables the development of theories while remaining

open to interpretation and layers of understanding. Consideration here was placed on the idea of using multiple case studies (ibid., p. 725) which enables relationships to be drawn between them, building on prior information in order to see pluralistic information from a range of angles – what they refer to as "sensitising concepts" (p. 733). Theory shapes what is focused upon during the research, but during the analysis it is the evidence itself which is at the forefront of the research as the data is broken apart and then reconnected. Prior knowledge enhances understanding, playing a role in how research is understood, but is not the only concern – during analysis, the emphasis has to be on the data rather than the theory, to ensure that a researcher does not simply find what they wish to see. Theory needs to emerge from the data, rather than the reverse.

Although the researcher's identity, beliefs and values do have an impact in the creation and analysis of qualitative data, careful coding should allow factors to be picked out even when they are not the result which the researcher wished for. The process of writing up examines how the research was conducted, justifying what happened and acknowledging any limitations to the methods used. The goal for analysis is to turn the data gathered from the case studies into useable information by highlighting repeated concepts and examining how these are interlinked. By doing this using an iterative process, theories could be developed and discoveries drawn out from the data itself.

Which Case Studies?

Having considered the methodology and methods which would be used, it became necessary to select suitable cases for my research. Unlike within quantitative research, cases within qualitative research are not chosen randomly, but are instead "chosen on the basis of their distinctive features" (Denscombe, 2007, p. 56).

There are numerous museums within the UK which contain objects which could be used to tell disability narratives. The challenge was to narrow the selection of case studies so that truly in-depth and valuable knowledge could be achieved. Initially I produced a long list of sixteen potential case studies, with the goal of narrowing it down further in order to ensure the cases selected were those which would enable me to learn the most.

Denscombe (2007) speaks of three types of case study: the typical instance, the extreme instance, and the least likely case. The typical instance is one viewed as similar to other potential cases and therefore knowledge gained here is likely to be more widely generalisable. In contrast, the extreme instance is "something of a contrast with the norm" (ibid., p. 57) – a case which is in some ways unusual and unlike other potential cases. The least likely case is one where certain results seem least likely to appear. If the result viewed as least likely was found in that particular case study, it implies that it may well hold true of all possible examples.

When selecting my case studies, I decided to use cases which are to some extent 'extreme', picked out because they enabled me to look at a particular issue in a higher level of detail. With the goal of researching disability narratives and their presentation, it was important to consider sites which would contain a high number of such stories, and I chose cases that were open during 2018 as this was the period in which I was completing my fieldwork. However, the use of a number of contextual examples aimed to increase the generalisability from these extreme cases, by examination of what happened in a range of different sites. My research was also framed by consideration of the social model and a desire to discover who was shaping the narratives which were being told, as well as practical issues of timing – I wished to use case studies that were open during my research, and for which I would be able to talk to key staff.

Ultimately, I reached the decision to focus on three sites, as well as using further contextual examples, each of which had been selected to illustrate a different aspect of museum work and disability narrative. The three case studies were the Science Museum (London), the Museum of Liverpool (Liverpool) and NDACA (Online and Buckinghamshire).

The contextual examples were selected because although they had a smaller amount of disability related material, I felt that they would also have something to offer my research. These sites were the National Army Museum (London), the Wellcome Collection (London), the Imperial War Museum (London), the National Maritime Museum (Greenwich), and the Bethlem Museum of the Mind (London).

The Science Museum London's exhibition *Wounded: Conflict, Casualties and Care*, was chosen because it is a site which could perhaps be expected to focus on the medical model of disability, due to the site's focus on the history of medicine (Snyder and Mitchell, 2006). It ran from the 26th June 2016 to the 3rd June 2018, considering both immediate treatment and longer term care of injured soldiers, and examining the treatment of PTSD in both the First World War and modern conflicts. In addition, on 28th February 2018 I attended a symposium held at the Science Museum which examined the development of the exhibition and offered an insight into the narratives they aimed to explore. Finally, the Science Museum was undergoing the process of reshaping its Medicine Galleries, and many of the staff who were involved in the development of *Wounded* were also involved in this redisplay. I wished to understand what they had learned from this process and how it shaped their future presentation of disability during the development of the Medicine Galleries and in other future work.

The Blind School: Pioneering People and Places at the Museum of Liverpool was selected as it was a temporary exhibition (running from the 26th January 2018 until the 15th April 2018) which aimed to be accessible and was from a museum with an explicit focus on telling diverse stories and supporting human rights. This therefore provided a greater opportunity to understand how disability was shown by a museum which had deliberately chosen to present a particular side rather than attempt neutrality, linking to ideas discussed within prior chapters. In addition, it involved cooperation between the museum and the disability-led History of Place organisation, which I wished to research in more detail.

NDACA, the National Disability Arts Collection and Archive, offered the opportunity to examine a disability-led archive, one which focuses on the heritage and history of disability and which aims to allow "disabled people to realise their own heritage and bring non-disabled people closer to the struggles that they have been faced with" (NDACA, 2018). It opened online on in April 2018, and on-site on the 2nd May 2019. The involvement of disabled people throughout the process, and the focus on disabled heritage as the driving force behind the creation of this archive, meant it was unlike other cases, and gave an opportunity for disabled voices to be made audible in my research.

Contextual examples were chosen due to the way they could provide additional perspectives to these case studies. I wished to see how disability narratives were integrated with wider stories of conflict, something which an examination of the National Army Museum enabled. This was further supported with the Imperial War Museum's *First World War Galleries*, which shared a time period with the Science Museum's *Wounded* exhibition, enabling comparison. The Wellcome Collection had recently completed a redisplay for the *Being Human* gallery that had involved working alongside disability rights campaigners and artists. The *Nelson, Navy, Nation* gallery at the National Maritime Museum contains several objects linked to Admiral Nelson, a man who is probably Britain's most famous disabled war hero. The time period discussed is one where injury and disablement were common, and I wished to investigate how the link to disability was drawn out. I selected The Bethlem Museum of the Mind as it aims to include patient voices, and I wished to understand the process by which this was done and its effectiveness. I felt each of these examples brought something additional to my research.

Although this meant that the majority of my case studies are based within London, two of the case studies (NDACA and the Museum of Liverpool) are located elsewhere in the country, enabling me to look beyond the capital. In addition, I chose these cases not because of their location but because of their content, and therefore feel that my research should still be meaningful for those who are based outside London.

Practicalities and Ethical Issues

There were a number of practical and ethical issues which I had to take into consideration at the commencement of this project. The practical issues included ensuring access to relevant sites, records and staff. This was done by contacting the museums I had identified and explaining my research, going through the necessary gatekeepers to access staff involved in the curation and display of the objects I wished to study and the creation of the exhibits I was focusing upon.
A further practical issue that occurred during my research was the global coronavirus pandemic, which began in the March of 2020. This was after I had completed my fieldwork, but curtailed any opportunity of visiting other sites or carrying out additional

interviews, and caused a great deal of uncertainty. It also necessitated a restructuring of the writing process, as libraries were closed, and put a temporary halt to the kind of collaborative projects which I was researching. However, by careful time management, I was able to complete the thesis.

Ethical concerns involved considerations of confidentiality and of maintaining positive relationships with the case study museums when looking at a topic which had the possibility of being both challenging and emotive. An ethics application, following the University of Leicester's guidelines, was submitted on 17th July 2018, and returned on 6th August 2018. The key considerations which were brought up with this were considerations of consent and anonymity.

All participants were provided with information sheets and consent forms prior to the commencement of the study, which are included in Appendix B. These set out the main goals of the research and a rough outline of the kinds of questions that would be asked. This therefore gave potential participants the opportunity to withdraw if they did not feel comfortable with the topics being discussed. My participants were museum professionals and representatives of groups who had co-curated displays, with the focus throughout being on the representation of disabled individuals shown in these displays, along with past and future displays that these individuals were or would be involved with.

As the case studies have been identified, alongside the roles of the participants, the participants were identifiable. They were made aware of this from the very beginning of their involvement and were able to decide whether they wished to be acknowledged by name within the research – something which they all agreed to. Whilst the topics examined could potentially invoke strong emotions, the focus was on museum representation rather than disabilities or personal experience. This museological lens allowed a challenging topic to be approached at a remove, which reduced the risk of causing distress. The topic was treated with sensitivity and respect with consideration given to the participants, who had the opportunity to request a pause if needed or skip any questions that they wished.

Throughout the process, I made sure that consent was gained from the participants, and ensured they understood they could withdraw from the study at any time. As the initial invite contained the kind of information I was looking for, they were able to decide whether to give their initial consent from a position of knowledge. In addition, I used 'member-checking', offering to return the transcripts of interviews to participants so that they could ensure that their views were correctly represented. This both allowed for participants to clarify points that they had made and increased the validity of my study. Such validity was also increased by triangulation between different sources as this was used to build a coherent and corroborating justification of themes (Creswell, 2003), both within and across the different cases. Ensuring that points made were valid helped to meet the ethical demands of such research, as it helped ensure that I accurately presented what had been said.

Conclusion

This methodology chapter has explored the philosophies and principles behind the use of the qualitative approach and the application of case studies. Consideration has also been given to other relevant methodologies, in particular the understanding of emancipatory and values-centred research. The kinds of data collected, and the subsequent analysis of this data, was investigated, as was the selection of the case studies and the ethical and practical considerations which shaped the investigation from the commencement of the project. Having examined the methodology which guided the research undertaken, attention now moves to the case studies that were used, and the data that has been gathered from them, in order to understand how disability is presented across the various museum sites.

Chapter Five – Narratives of Representing Disability

Introduction

This chapter focuses on how museums represent disability and the narratives that they share within their exhibitions. Having already discussed the literature around museum narratives of difference, and disability representation in the public realm, I now move my focus towards the case studies that I have used within this research and what it is possible to learn from them. The last chapter, concerning the methodology, explained the motivation for the use of case studies, the data sources used, and how the data that was collected was analysed.

In this chapter, I begin by setting out in detail the case studies that were used and the data which was gathered from them. I also explain the contextual examples which I have used in order to develop certain points. I then will examine various elements of the case study exhibitions in more depth, considering how the layout and language of the exhibitions represent disability: how it is shown through media within the galleries, as well as external communications including advertisements outside of these spaces, and how disability is presented on the museum websites.

Once this is done, I consider the ways that this presentation relates to stereotypes of disability discussed within Chapter Three, querying the extent to which these portrayals have challenged, reinforced and potentially subverted stereotypical depictions of disability and disabled lives which were considered within my literature review. I also examine new narratives that have been highlighted across the different sites, before concluding with an overview of what has been revealed about how these sites represent disability. Having explored what makes up the physical and online space of these exhibitions, in the following chapter I move on to consider whose voices were heard in these representations, alongside evaluating why this is important.

The Case Studies

As explained within the methodology, I chose to focus upon three main case studies, analysing each of them in depth. Looking at three case studies allowed me to examine in detail how they were approaching disability representation, whilst also being able to draw comparisons between the different cases. The three main cases which I used are set out below.

***Wounded: Conflict, Casualties and Care* – Science Museum:**

A free special exhibition displayed for two years (26th June 2016 – 3rd June 2018) within the Science Museum, London, *Wounded: Conflict, Casualties and Care* (abbreviated to *Wounded*) focused on the "huge medical and human impact of wounding during and beyond the First World War" (Science Museum, 2018a). Alongside looking at medical innovation, the exhibition considered the longer-term impact of the war on those who fought, including on their later care. There was a participation project as part of the exhibition, in which veterans with PTSD co-produced a film and an exhibition case about their own experiences of conflict. In addition, on the 28th of February 2018 the site hosted the 'Wounded Symposium' (Science Museum, 2018b), which was a one-day event exploring the creation of the exhibition and its main themes.

The Science Museum is a national museum, attracting over 3,250,000 visitors in 2017 (ALVA, 2018), making it the sixth most visited site in the UK. Focused on human ingenuity and scientific achievement, it has recently redisplayed its Medicine Galleries, which opened in mid-November 2019 with many of the staff involved in the development of *Wounded* also working on this project. I was able to attend the 'Medicine: the Wellcome Galleries Conference' on the 23rd to the 24th January 2020, which celebrated the opening of these new galleries and detailed their creation (Science Museum, 2020a).

This site was selected because it is a site that might traditionally be expected to focus on the medical model of disability, since it was founded to look at science and scientific progress. Indeed, as will be discussed below, a senior member of staff expected the focus of the exhibition to be on the "triumph of medicine" (Emmens, 2018). However, instead a far more complex picture emerged. This followed other work done by the

Science Museum, with increasing collaboration with disabled groups, including work with Matt Fraser (RCMG, 2019). I hoped to discover how these collaborations were altering the work of this site, and how its focus had shifted over time.

The Blind School: Pioneering People and Places – Museum of Liverpool:

The Blind School: Pioneering People and Places exhibition (abbreviated to _The Blind School)_ was a temporary exhibition within the Museum of Liverpool (26th January – 15th April 2018), created in collaboration with the History of Place project. The exhibition aimed to tell the story of Liverpool's Royal School for the Blind. This was founded in 1791 by blind abolitionist Edward Rushton, the first school for blind people in Britain and the second in the world. Looking over its 227 year history, this exhibit worked on "challenging people's attitudes towards blind people, past and present" (Liverpool Museums, 2018b), using a variety of objects and stories in order to do this. The exhibition aimed to be accessible, and included audio description, braille, British Sign Language interpretation and multisensory features such as hands-on objects and tactile reliefs.

The History of Place project ran from 2016 until 2019, in order to explore 800 years of disability history across eight sites (History of Place, 2019). It involved historical research, the creation of blogs, the development of toolkits, and three exhibitions – at MShed in Bristol, the Museum of Liverpool, and the V&A in London. It aimed to provide an overview of disability history which had previously been absent.

The Museum of Liverpool attracted over 700,000 visits in 2017 (ALVA, 2018). The mission of National Museums Liverpool, the group to which it belongs, is to be "the world's leading example of an inclusive museum service" (Liverpool Museums, 2018a). The group explicitly aims to maximise "social impact and educational benefit", engaging with contemporary and at times controversial issues in order to drive for social change and social justice. In this, the museum does not attempt neutrality, but instead embraces the opportunity to argue for the rights of those represented. It is therefore on the leading edge of using a collaborative approach. I was interested in discovering the extent to which this ethic guided the museum's _The Blind School_ exhibition, and how the museum included disability more widely within their work.

NDACA (The National Disability Arts Collection and Archive):

The website of the National Disability Arts Collection and Archive (abbreviated to NDACA) first went live in April 2018, and the physical site opened in May 2019, aiming to bring to life "the heritage and rich history of the Disability Arts Movement" (NDACA, 2018). The Heritage Lottery Fund project was delivered by Shape Arts, a disability-led organisation that aims to provide cultural access for disabled people, creating opportunities and training cultural institutions to be more open to working with them (Shape Arts, 2020). NDACA aims to use both its online resources and physical space to trace this story from the 1970s until the present day (NDACA, 2018). It has been designed to enable disabled people to see their heritage, and to explain "the barriers of a disabling world" to non-disabled individuals. The collection consists of oral history films, an online archive of over 2,000 images, interactive learning resources and accessible research facilities. By December of 2018, the website hosting the archive had received over five million visits (Hevey, 2018).

This particular case study was an opportunity to examine work that had been created by and for disabled people, as well as giving the chance to explore an archive that had only just been launched and in doing so speak to the creators about their goals during its development. This recent project provided a contrast to the other museums – the Museum of Liverpool having opened in 2011, replacing the former Museum of Liverpool Life (Liverpool Museums, 2019), and the Science Museum having first opened as part of the South Kensington Museum in 1857 (Science Museum, 2019). With its primary focus on disability, this site enabled me to look at a collection which had this, rather than science or social history, as its core. I hoped this would allow for further contrasts to be drawn.

Interviews:

When carrying out my case studies, I used exhibition analysis, website analysis, and interviews with museum staff. All of my interviewees gave their permission for their names and roles to be used. The table below records the interviews that were undertaken.

Site	Date	Name of Interviewee	Role of Interviewee	Duration
Museum of Liverpool	15/08/18	Esther Fox	Head of Accentuate	35:29
Museum of Liverpool	21/08/18	Esther Fox *	Head of Accentuate	18:29
Museum of Liverpool	02/10/18	Kay Jones	Curator of Community History	44:33
Science Museum	14/11/18	Natasha McEnroe	Keeper of Medicine	19:07
Science Museum	14/11/18	Stewart Emmens	Curator of Community Health	1:15:26
Museum of Liverpool	05/12/18	Charlotte Kingston	History of Place Curator	52:28
NDACA	09/12/18	David Hevey	Project Director	32:42
NDACA	16/04/19	Alex Cowan	Project Archivist & Collections Lead	49:43

* Due to technical problems, Esther Fox's interview was carried out in two sections.

Contextual Examples

Alongside these three main case studies, I made use of a number of contextual examples which were able to supply additional perspectives and information, enabling my research questions to be addressed in a range of different ways. While my case studies are examined in depth and run throughout the essay as a whole, the contextual examples are instead used in order to think about and comment on details from the case studies. They serve an illustrative purpose, showing the broader context of a field of practice, in which my case studies are situated, as well as increasing potential generalisability as discussed within the methodology section. By allowing further correlations to be drawn, these examples increased the likelihood of my findings applying more widely.

The National Army Museum: The National Army Museum examines the role of the British Army from the British Civil Wars to today, sharing "stories of ordinary people with extraordinary responsibilities" (National Army Museum, 2019a) and considering the army's relevance in times of conflict and peace. It reopened in 2017 and explores relationships between individuals, society and the military (National Army Museum, 2019b). This contextual example was chosen to allow a deeper examination of how disability narratives have been integrated within wider stories of conflict. As with the Imperial War Museum below, I was inspired by Carden-Coyne's work (2010) on the treatment of disability by war museums, which often choose to valorise death whilst ignoring the life-long impact war can have on those combatants and civilians who are disabled by their involvement in the conflict.

First World War Galleries – **Imperial War Museum:** The Imperial War Museums are a collection of five museums which record and explore conflict and the impact it has on people's lives. IWM London aims to "tell the stories of people whose lives have been forever impacted by conflict, from the First World War to the present day" (Imperial War Museums, 2018b). The 36th most visited attraction in the United Kingdom, IWM London had nearly one million visits in 2017 (ALVA, 2018). Such a large audience provides the IWM with a high level of cultural authority, meaning that the ideas it shares will reach a large number of people.

My focus for this case study was on the *First World War Galleries* – in particular, I hoped to compare and contrast the information they had about treatment and disability with the *Wounded: Conflict, Casualties and Care* exhibition at the Science Museum. Carden Coyne (2010, p. 67) explains that war museums often overlook disability as the impact on lives "eclipses any discussion on the complexities of justice" and is something which audiences would rather avoid. I was therefore curious to see how the IWM handled this topic in their *First World War Galleries*, which were redeveloped in 2014 and which claim to show the war's "impact on people's lives across the globe" (Imperial War Museums, 2018a).

***Being Human* – The Wellcome Collection:** The Wellcome Collection "aims to challenge how we all think and feel about health" (Wellcome Collection, 2019a). Since its establishment in 1936, the Wellcome Trust has aimed to improve health globally. On the 4th of September 2019, a new permanent gallery *Being Human* opened, with the goal of exploring "trust, identity and health in a changing world" (Wellcome Collection, 2019c). The gallery was created with input from two advisory panels – one of scientists, the other of disabled artists, activists and consultants who worked with the University of Leicester's Research Centre for Museums and Galleries focusing on the representation of disability and difference (Wellcome Collection, 2019b). I chose this as a contextual example due to my interest in the process through which this gallery was created, and in particular how collaboration with disabled activists shaped the end result. I had been lucky enough to be involved in this process due to work I had carried out with the Research Centre for Museums and Galleries (RCMG, 2020), and wished to draw on how the work aimed to create a permanent intervention embedding disruption and aiming to challenge "medicalised views of physical and mental diversity". This example was the second most recently completed site I examined (with only the Medicine Galleries of the Science Museum being later), and by including it I hoped to examine some of the most up-to-the-minute work that was being carried out within this field.

***Nelson, Navy, Nation* – National Maritime Museum:** Royal Museums Greenwich, of which the National Maritime Museum is a part, is one of the most visited museum sites in the UK, with over two and a half million visitors a year (ALVA, 2018). I chose to focus on the *Nelson, Navy, Nation* gallery, which tells the story of "a national hero" and encourages visitors to "discover a man who was brave and unconventional", as well as the history of the Royal Navy from 1688-1815 (Royal Museums Greenwich, 2018a). Nelson, a disabled war hero, is the key focus of this gallery, with his personal items and memorabilia proudly displayed. In addition, there are other relevant objects from this time – with the website mentioning "an amputation knife and bullet forceps" (Royal Museums Greenwich, 2018a).

Focusing on a point in history and a career in which injury and disablement would have been common, and featuring an individual wounded in conflict, this case study enabled me to see how disability was presented alongside other historic narratives. It was the

one example I looked at which was primarily centred upon a single disabled individual, and therefore I was curious as to how his story would be told and his impairment presented.

Bethlem Museum of the Mind: Bethlem Museum of the Mind is a modern museum which focuses on mental illness, opening formally in March of 2015. It contains an "internationally renowned collection of archives, art and historic objects" (Bethlem Museum of the Mind, 2018), examining the history of mental healthcare and treatment. In the grounds of Bethlem Royal Hospital – the first hospital in the UK to specialise in the care of the mentally ill, founded in 1247 and continuing with this work today – the museum aims to foreground patients' voices, working with current clients of mental health services. Unlike the other case studies, this museum concerns itself with mental health, and is embedded within the community that it depicts. I chose it due to its use of patient voices, and its unique focus and location.

All of these contextual examples were selected because they work together to show a range of different sites, each with their own unique stories to tell, whilst also combining to provide a rich and deep coverage of disability and disabled history. They therefore enabled me to examine how stories of disability and disabled people are represented across a number of locations, to explore the factors which shaped the narratives told, and to consider the implications which they have on contemporary debate.

Case Study Aspects

Having set out my case studies and contextual examples, I now aim to look at different aspects of these exhibitions for how they contribute to the narratives that are being woven around disability, and how they link to the social and medical models. Initially examining the layout of the exhibitions, I then consider the role of media within the space and how it enhances accessibility, before I move on to look at the language used within the exhibition, then finishing by evaluating the external communications

surrounding the sites. These combine to give an overall impression of how the museum is tackling this topic.

Aspect: Layout and Location

The layout and location of any exhibition is important. As Sandell (2005, p. 185) explains, museum spaces are often viewed as a "means through which social inequalities have been constituted, reproduced and reinforced" – whether or not a certain group is represented within a gallery, and if so where that representation is, shows the value (or lack of such) placed upon that group. An absence is a devaluing, a message saying that the group that is missing is not worthy of attention.

Sandell (2005, p. 190-191) analyses the different ways that minority groups are included within exhibition spaces. He sets out three models of inclusion, the first two of which are peripheral and temporary, suggesting "lesser importance for the groups represented by such transient displays":

- Compensatory: small-scale temporary displays, often a small case with little change to key exhibits, sometimes carried out as a reaction to criticism.
- Celebratory: a more prominent display with higher profile, often working with a particular group's collaboration and highlighting their achievements.
- Pluralist: traditional inequalities are challenged by changing allocation of space, proactively collecting and redisplaying museum spaces.

By creating these three models, Sandell is not arguing that one is the superior form of representation. Indeed, museums will often use a combination of models at different times, or for different groups. The model used will instead depend on the goal of the representation. The three case studies I used each included an element of one of these models.

***Wounded*:**

The layout of *Wounded* was designed to evoke an injured soldier's journey. Throughout the exhibition's various design iterations, the curator's idea was to examine

> "…a sort of boom moment of wounding, what happened in the seconds, minutes, hours, days, to someone wounded." (Emmens, 2018)

The entry to the exhibition was through a tunnel representing that moment, and Emmens expanded on this by saying

> "…there's that bit of intro but then there's that funny little tunnel bit, which… was sort of to represent that moment. Not that everyone had a moment of wounding, but that sort of beginning of that journey, away from that moment of wounding which could go on for the rest of your life effectively." (ibid.)

The main body of the exhibition focused on this aftermath, and this pathway was shown within the exhibition design itself (Figure 5.1).
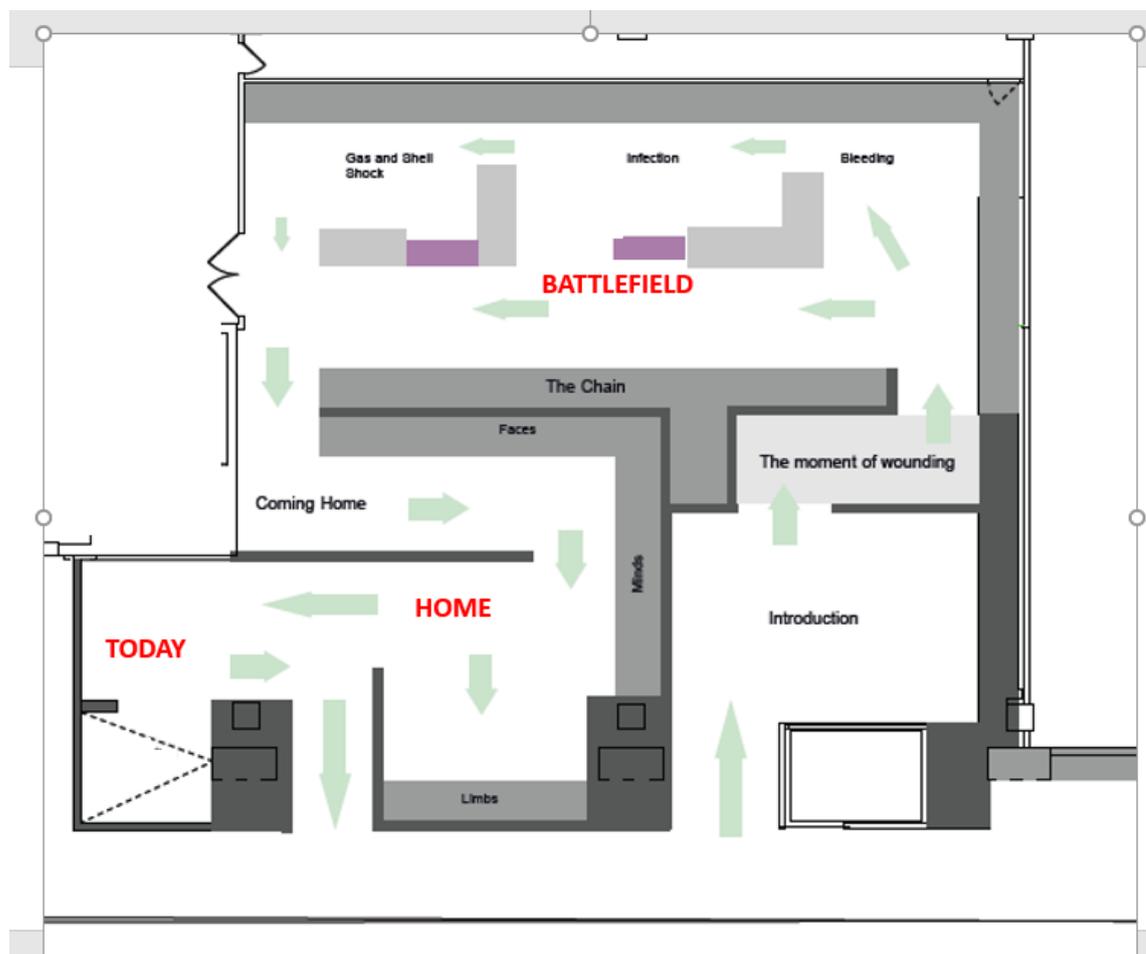
Figure 5.1: Layout of the *Wounded* Exhibition (Designed by Stewart Emmens)

The visitor initially was presented with some general information about the war, before going through a tunnel which featured a light display to represent the moment of injury itself, lined with fragmented short quotes from those trying to recall their wounding (Emmens, 2020). This highly stylised presentation of a flash of bright light relied on visitors making their own meaning from it and drawing on their own understanding

(Gro Gundersen and Back, 2018). The visitor was then presented with information about battlefield injuries, with sections focusing on bleeding, infection, gas and shell shock, while down the side there ran a number of exhibits representing the chain of evacuation. After that, they went through to a section about the ongoing treatment these soldiers, now patients, would face. These treatments were divided based on the kind of wound received, with sections looking at injuries to faces, minds, and limbs. At the end of the exhibit, the visitor had a choice between exiting the exhibition, or continuing on to the 'Wounded Today' section, which contained a co-produced film and display case alongside information and films about current medical treatment.

Although representations of disability caused by war are visible throughout the exhibition, it is only in this final room that the voices of disabled individuals are heard, something which will be discussed in more depth in the next chapter. To some extent *Wounded* followed Sandell's compensatory model, with the collaborative work tucked out of the way towards the end and missed by many visitors. However, there were a range of reasons for this: the time period had shifted from the First World War to the present day, and touched on topics which might be painful for some visitors. Although the collaborative work was of a small scale, it was still a valuable learning experience for the staff and significant to those who took part, as will be examined further within Chapter Six.

The location of the exhibition within the museum led to some difficulties. It was placed on a mezzanine level. While this meant that it was near the main entrance to the museum, for a wheelchair user to access it they would have to go past the exhibition and use a lift, before then returning to the exhibition. This contrasts with the new *Being Human* Gallery within the Wellcome Gallery, which was designed to give precedence to the wheelchair-accessible entrance.

***The Blind School*:**
The Blind School exhibition was divided into five different sections, as shown in Figure 5.2. The exhibit told a story, looking first at the origins of the school, then the school's relationship with the city, before looking at crafts and leisure, life at the school, and an explanation of what life is like for blind people. In this way the layout is used to both

expand geographically from the school to the city's history, and also move forwards in time from the school's foundation to the present day. Temporary walls were constructed to enclose the exhibition and to separate it off from the rest of the space, as the Skylight gallery where the exhibition was sited leads to two other exhibitions.
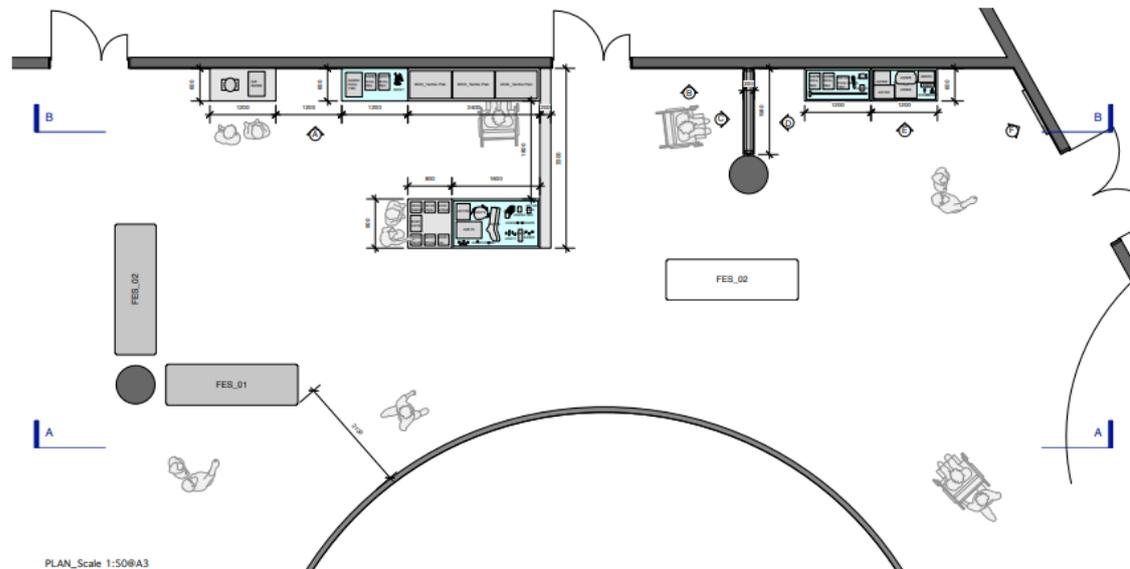
Figure 5.2: Layout of *The Blind School* exhibition (Provided by Charlotte Kingston, Sarah Pollard for 3D and Fernando Lai Couto for graphics)

While *The Blind School* exhibition was temporary, it was also highly collaborative and therefore close to Sandell's celebratory model. In addition, disability stories are included throughout the Museum of Liverpool. As Kay Jones, Curator of Community History, explains, within the Wonderous Place gallery

> "… there were physical lockers which you opened and there were people's individual stories and audio which kind of started when you opened the locker, and we had Paralympic athletes' stories in relation to that, and also within the *King's Regiment* galleries we have a t-shirt of a man who played for the England Blind Football team, so even in content that you might not expect to see disability representation, we've made sure that there's diverse stories reflected wherever we can." (Jones, 2018)

This reflects the pluralist model, and shows an attempt to include these stories as part of Liverpool's history, rather than simply putting them to one side as something that only a

few people would be interested in. The exhibition was positioned in the Skylight Gallery, a "bit of a tricky space" (ibid.) which had only previously been used for photographic exhibitions. Despite issues with sound bleed, placing this exhibit right at the heart of the museum suggests that it was seen as valuable. Most visitors to the museum would walk past the gallery on their journey to other galleries, and its semi-open layout served to invite them to take a closer look.

NDACA:

Whilst much of NDACA's work is online, they also have "the first ever study space dedicated to the heritage of the Disability Arts Movement" (NDACA, 2019b), and it is to this space that my attention now turns. The NDACA website proudly states that "access for disabled people is an intrinsic part of our design", and this can be seen in the layout (Figure 5.3).
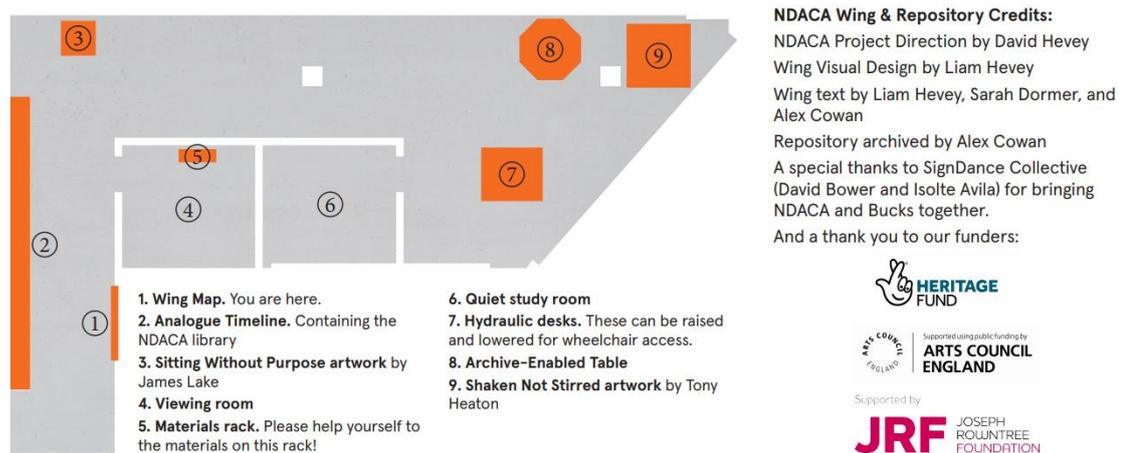
Figure 5.3: Layout of the NDACA Wing (Map designed by Liam Hevey)

The archive itself is a small room full of boxes and artwork (Figure 5.4), which have not yet been fully processed. However, the study space contains a quiet study room and a viewing room for those who are using the archive, and these spaces have been designed to be accessible, including wide spaces and hydraulic desks. The space is set out with room for wheelchair users to manoeuvre and features several artworks and information boards.

This site is the closest of my case studies to the celebratory model within Sandell's description, as here the work of the Disability Arts Movement is looked at in detail and

celebrated, rather than integrating it within a wider museum. However, unlike the other case studies which I have looked at, this is a permanent study space that is open to everyone.

> "It's set up to allow public users. The idea is if you want to access, you can access the catalogue, and then you can fill in a form on the catalogue, and say you'd like to view them on these days, so it's open for business for everybody. And then the staff have been trained – have had their disability awareness training, and also you know… understand that it may be members of the public as well." (Cowan, 2019)

Figure 5.4: Boxes and papers within the NDACA archive (Photograph by Jenni Hunt)

By being open to all, the hope of the curator is that the NDACA space will be able to widely share the Disability Arts Movement story. The NDACA Wing is located within Bucks New University Library, with plans to encourage both outside researchers and students of various topics at the university to make use of the resource, alongside members of the public. Since opening, work has already been carried out involving both

nursing and fine arts students, and in doing so attitudes around disability may be challenged and changed.

Comparison:

The three sites can be seen to represent the different models that Sandell (2005) suggests – *Wounded* as a compensatory exhibition, NDACA as a celebratory one, and the Museum of Liverpool's wider coverage of disability as pluralist. However, none of the exhibitions fit neatly within this schema. Furthermore, the different types of exhibition do not form a hierarchy – instead, all of these methods reflect different ways of portraying differences, and work towards different goals. Having disabled individuals represented within a gallery as prestigious as the Science Museum has an impact, as does having dedicated disability-focused spaces. Only by using a combination of methods can positive outcomes be achieved.

Aspect: In Gallery Media and Accessibility

Museums use a variety of ways to make their material accessible to their audiences, including the use of in-gallery media, such as films, images, and tactile displays. This accessibility will affect the extent to which disabled audiences are able to engage with the material that the museum presents – for example, object handling can enable "tactile engagement and playful encounters" (Dodd and Jones, 2014, p. 26) which allows conversations and learning to occur. The purpose of this section is to examine the range of media used within the exhibition spaces of the case study, and to consider how they link with ideas of accessibility.

*Wounded***:**

There were various forms of media within the *Wounded* gallery. There were no tactile objects within the display, and no audio guide. However, there was an interactive display showing different treatment centres that wounded soldiers were sent to (Figure 5.5). The focus here was on those who organised and ran the treatment centres, rather than the patients themselves, a pattern seen throughout the exhibition where the

emphasis was often on those who carried out medical advances, rather than the people that they were treating.
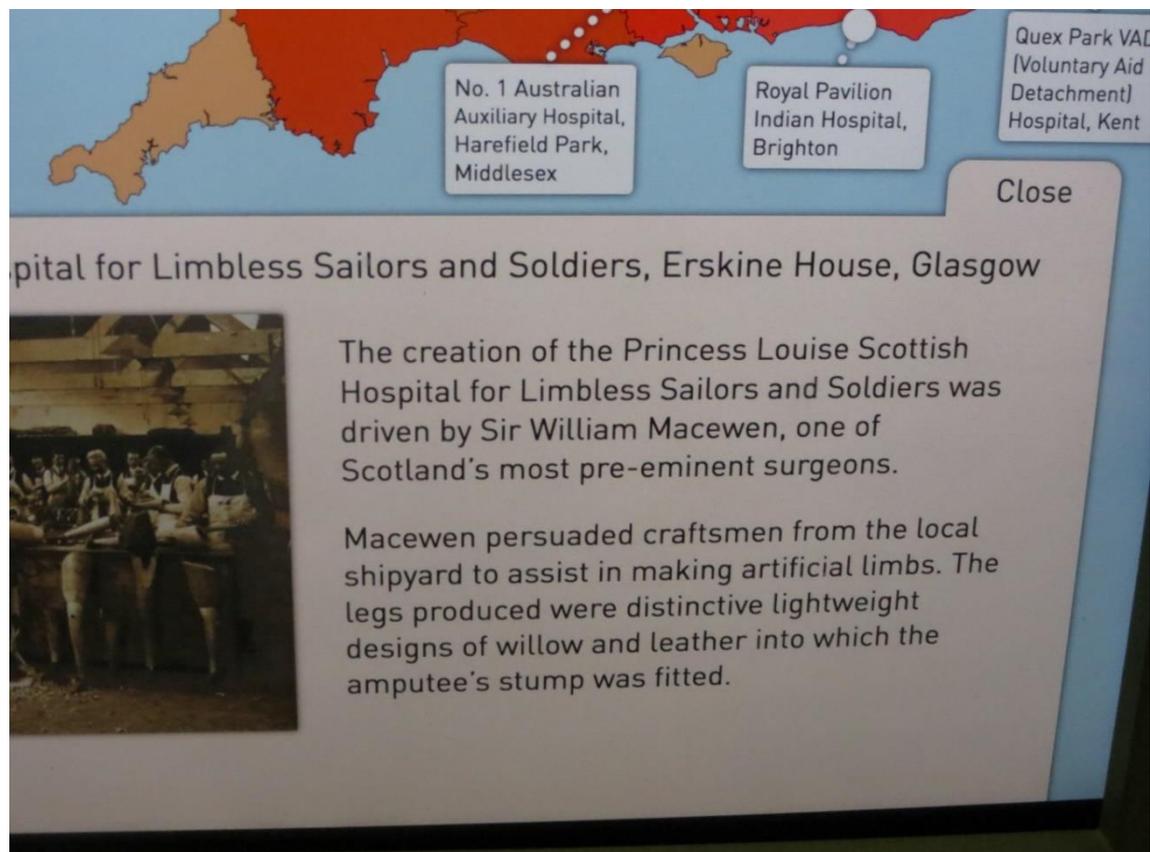
Figure 5.5: Information on an interactive about the Hospital for Limbless Sailors and Soldiers within the *Wounded* exhibition (Photograph by Jenni Hunt)

There were also four films within the exhibition. In the historic part of the exhibition, there was one consisting of archive footage showing the chain of evacuation, and a second showing rehabilitation activities. In the modern section, there was a film which compared frontline medical treatment now with that on the Western Front, and the co-produced film which will be discussed in greater detail within Chapter Six. Where relevant, these films were subtitled – the film showing rehabilitation activities did not feature any dialogue.

Wounded had some accessible features, like many exhibits within the Science Museum. Display cases were set at heights found to be appropriate for a range of users, and wide corridors allowed for groups to travel the exhibit together and for wheelchair users to be able to manoeuvre. The curator was aware of the limited accessibility:

"... I don't know if they did a braille book in the end, that's always a difficult one because you know, that's only catering for a very small proportion of people you know with sight issues. But you know, there wasn't huge amounts of those sort of concessions." (Emmens, 2018)

Part of the reason for this lack of accessibility was because the exhibition was temporary, which could lead to the decision not to invest in an element which would not be useful to many people. When the site has a limited budget for accessibility, they may choose to prioritise investment in accessibility for permanent exhibitions. However, while this exhibition lasted for two years, this temporary nature was also true of the Museum of Liverpool's exhibition, which was in place for only three months.

***The Blind School*:**
The Blind School exhibition was designed with accessibility at the forefront, with information presented in a number of different ways.

"Of course, we wanted the exhibition to be as accessible as possible, so in addition to the BSL, the braille guides, there were smells within the exhibition as well, obviously audio points, the curator-designer designed it with a yellow band around the exhibition to help guide and orientate people around the exhibition, and all the AV elements, so we tried to be as accessible as possible. I don't think any exhibition can be 100% accessible but we tried." (Jones, 2018)

This accessibility was viewed as central to the exhibition design, with Fox (2018b) explaining that all the stories shared were

"…interpreted in a number of different ways. So it could either be interpreted for a visually impaired person using audio description, or using tactile models, or it could be also interpreted for a BSL user because the film had been interpreted and so had the text panels, and those kinds of things. So we tried to find different ways of telling the same story but in different interpretation methods."

This was done to try and ensure that the stories told were as accessible as possible to a range of people. This concern with accessibility was reflected within the design of the

exhibition, which contained a number of tactile models and touch exhibits, as seen in Figure 5.6. It was also evident within the external communications of the exhibition, as will be discussed below. Beyond that, the staff were trained to consider issues around accessibility, with one of the former pupils of the Blind School coming into the museum in order to provide training for the staff.

Figure 5.6: Tactile and scented exhibits of a basket, rope and a sock shown within *The Blind School* exhibition (Photograph by Jenni Hunt)

This training provided particularly useful information for those who participated, as not only did the ex-pupil talk to staff about guiding visually impaired people within the museum, but he also got them to consider what would help people in getting to the museum in the first place. There is a major road (The Strand) that has to be crossed prior to arriving at the Museum of Liverpool, and the former pupil encouraged the staff to think about "other challenges that people are going to have to know about" (Jones, 2018), such as how to actually reach the museum. This is an issue that the museum is working to embed throughout their work, reaching out to the public to help them get to the museum, rather than simply defining the visit as starting at the museum's front door.

The hope with this is that it will improve the museum's offerings and increase take-up by disabled audiences, whilst also making the site more welcoming to all visitors.

There was also an audio guide provided. Unlike previous exhibitions, where the audio guide had focused simply on description, here the audio guide was used in a creative way. The aim was not just describing what was present but also using disabled voices to tell stories around the exhibition – this will be discussed in more depth in Chapter Six. In this way, the audio interpretation served as a further layer of depth to the exhibition, providing another way for the visitor to engage with what was shown.

> "Kerry worked with an audio describer for the exhibition – but using that in a very creative way, rather than just, obviously it would help orientate people and gave them ideas of the space but it also worked as another narrative for the exhibition content. You could download those on the exhibition website before you came to the exhibition or you could do it there and then." (ibid.)

This creativity was designed to benefit all visitors, and give information in a fun way alongside increasing access.

However, not everything done to try and ensure accessibility at the museum was successful. The main thing that Kay Jones felt she had learned from holding this exhibition was to get someone to check the braille, as one of their braille guides had been mixed up with one about a theatre elsewhere in the country. The guides had been made by a professional company, but as they hadn't been independently checked, the mistake was only discovered by a visitor. After this, all of the braille labels within the museum are now being checked to ensure accuracy, in order to try and ensure that such mistakes are not repeated. This shows that learning is taking place, as the museum site aims to improve its offering for disabled audiences.

In addition, because of the mixture of people involved (as discussed further in Chapter Six), there was disagreement about how to best carry out certain elements within the exhibition. One example of this was the use of an iPad, which contained the BSL introduction for the exhibition. Some of the museum staff felt that this would not be appropriate, due to potential issues with technology; however, the History of Place team decided to use it. The technology failed, meaning the introduction was not available for much of the exhibition's run within the site itself. The information remained available

online, yet the lack of its presence within the gallery was seen as negative, as it made the space potentially harder for Deaf visitors to access and navigate. A further example of this disagreement was around the navigation band – initial plans to place it on the floor were abandoned because of practical limitations, and instead it was positioned on the wall.

While *The Blind School* exhibition was only in place for three months, effort was made to ensure it was widely accessible due to its content. The Museum of Liverpool generally tries to ensure all of its temporary exhibitions are accessible to some extent. However, because of the story being told, a higher amount of the budget was used to ensure accessibility (Jones, 2018). As will be shown in the external communications section, this led to positive results, as more people from disabled communities visited. However, it is unclear whether this increased uptake from disabled audiences will persist in other exhibitions which are not necessarily disability-focused, if such exhibits are made as accessible as these exhibits were. This is something that will become clearer over time, and which the museum is working to discover.

NDACA:

The NDACA wing is designed to be accessible. This can be seen in the layout (as discussed above), with wheelchair accessible desks and wide spaces. There are also tactile models of two key pieces of artwork (Figure 5.7) – *Shaken not Stirred*, and *Great Britain from a Wheelchair*. The original pieces were created by Tony Heaton, sculptor, chair of Shape Arts and initiator of NDACA (Shape Arts, 2019).
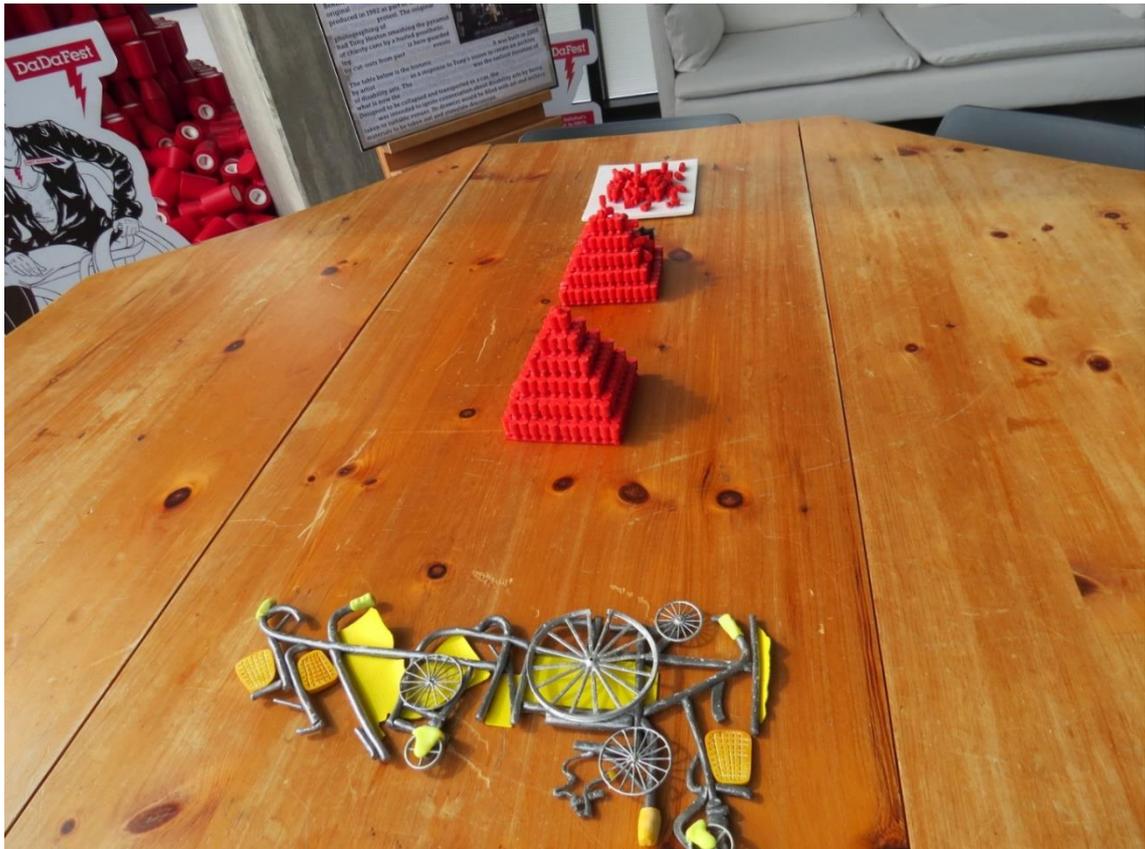
Figure 5.7: Tactile models of artworks on the archive table at the NDACA wing (Photograph by Jenni Hunt)

The NDACA wing is designed to be a permanent study space and accessibility has been considered throughout its creation, due to the content that it holds. The information around the walls is set at a height for wheelchair users, and content can be adapted as necessary from the archives (for example by creating transcriptions) based on the needs and requirements of users.

Comparison:

The three case studies have all considered accessibility within their design to varying extents. The methods used are varied, with both *The Blind School* and NDACA providing tactile models, and *The Blind School* using a detailed audio guide. Whilst the *Wounded* exhibit contained little extra in the way of accessible features, the presence of subtitles and the heights of cases used shows that the Science Museum is to some extent taking accessibility into account when creating all of their exhibitions: these

adjustments weren't made due to the nature of the exhibition, but are instead a standard part of their exhibition design process.

Aspect: Language

The language used around disability contributes to the "dominant regime of representation" (Hall, 1997, p.269), and frequently it can encourage negative stereotypes and ideas of pity and helplessness. However, I shall argue that all three case studies actively tried to combat this attitude throughout their work – this links to ideas of reclamation explored by Hevey (2010a). The negative language that can surround disability was seen within exhibitions explored by Dodd et al. (2004, p. 13) in which depiction was "limited, often reductive and stereotypical". However, in the time since then attitudes have shifted, with the language being used working to be more empowering and to emphasise agency (as shown by Garland-Thomson's 2010 work) rather than playing into stereotypes, and serving to present disabled individuals as a valuable part of society – a topic I shall return to within Chapter Eight.

***Wounded*:**

The lasting impact of the war is made clear from the opening panel of the exhibition, which states that:

> "The personal impacts of this war lasted for decades. The lives of many of those wounded in it were changed for ever. A more positive legacy for Britain lay in the development of new centres of medical care and welfare, providing specialist treatments and rehabilitation. Another outcome for society was a progressive shift in attitudes towards a generation of disabled veterans." (Science Museum, n.d.)

From as soon as a visitor arrives at the exhibition, the ongoing impact of the war is referenced, concerning its effects on individuals, on medicine, and on society. Rather than simply being framed as a tragedy, more complex concepts are addressed from the very start.

While *Wounded* focuses on the journey from an instant of wounding onwards, the lasting effects are being included – the idea that this is a lifelong impact, that persists

after the patient has returned from the hospital. Further on throughout the exhibition, the impact of the conflict on those wounded by it is again emphasised. The panel about survival states that:

> "many men faced years of further treatment and care back in Britain. In adjusting to profoundly changed circumstances, they had to learn new skills in order to regain some independence." (Science Museum, n.d.)

This statement is significant, as it both acknowledges the amount of assistance required by a soldier that had been newly disabled, and also acknowledges their agency in gaining new skills.

This agency was again shown in the description of the braille watches given to those who had been blinded:

> "A blind man's first contact with St Dunstan's came when he was presented with a Braille watch – gold for officers, silver for other ranks – while still under hospital care. The raised features on the face enabled him to tell the time by touch. This offered hope that a level of independent living would again be possible." (Science Museum, n.d.)

Emphasis is placed on the skills that have been developed by the individuals who were disabled, and the support that was provided to them in terms of prosthetics and training. This seems to intentionally challenge stereotypical ideas of pity, and refuses to allow disabled patients to be cast as passive or helpless.

Much of what is discussed, however, is the work of pioneering doctors such as Harold Gillies, and that of philanthropists such as Sir Arthur Pearson, rather than the experience of individuals who were disabled by the conflict. Although Sir Arthur Pearson was blind (Dark, 1922, p. 140), this is not mentioned within the exhibition – despite his disability being shared with those he was working with. This focus on philanthropy and the role of doctors was an intentional decision, which will be discussed in greater depth next chapter.

Attitudes towards disability are also discussed within the *Wounded* exhibition, with acknowledgement in the text of questions over financial support:

> "Despite the heroic status of the wounded, the realities of further care and financial support were worrying. The government provided pensions based on

the degree of disability, while charities, private philanthropy and the public

helped to resettle wounded veterans – although many of these schemes closed at

the war's end. For many of those returning the future was fraught with

uncertainty." (Science Museum, n.d.)

In this, the lack of support for people who were injured is highlighted, which is repeated

at certain points within the exhibition. This lack of assistance for rehabilitation is also

shown in discussion about mental health care, which acknowledges intersectional issues

by saying that "the options available could be fraught with issues of class, finance and

politics" (ibid.). By acknowledging the support that was meant to exist, and its failure,

the exhibit draws on the social model – rather than focusing on pity, it is the attitude of

society, and the lack of assistance, which are seen to be disabling these individuals

above and beyond the wounds that they have experienced during the war.

Despite primarily focusing on the roles of doctors in rehabilitation, the *Wounded*

exhibition also acknowledged the determination and strength of those who were injured.

The end panel of the First World War section says of those left permanently disabled:

"…some were terribly damaged by the experience, others were determined to

fight to reclaim a place in society. Many just quietly continued on their lifelong

journeys away from the battlefield." (ibid.)

Here again the impact throughout the life of those who were wounded is shown,

alongside their struggle to continue to exist and find a role within society, again

emphasising the agency of those affected.

Whilst the curator was not able to explore the impact over lifetime in the depth that he

wanted, to some extent this longer-term impact is acknowledged, as is the humanity of

those affected and their wide range of responses.

"You know, there was that sort of… Bang moment… all the battlefield stuff, all

the sort of immediate rehabilitation stuff… what's lost is that next fifty years or

something, when somebody… originally, when it was a bigger exhibition we

had some of that in, I don't quite know how we were going to represent it but

I… I mean I'm… I'm old enough to remember sort of family stories of grumpy

old men who had been in the war, who were coughing their guts up every night

and were… still affected by this conflict that had… that as a child seemed to

have happened in the previous century almost, you know, it seemed a long way

off and yet people were still talking about it and still seemed to be affected by it. And I kind of wanted to get some of that in, and in the end that was you know almost truncated down to that image [of a wounded veteran] – the image that was next to it, that quote, and a couple of other mentions, you know, a couple of objects which I tried to suggest… there was a fantastic artificial limb which has been repaired and repaired, and I… even though I don't really – I'm not explicit about it, I wanted that to suggest you know, somebody wore this for years and years and years." (Emmens, 2018)

The longer-term impact of disability as a result of war was something that would affect both the individual concerned and their community, and trying to present this was a challenge, with Emmens saying that he would have liked to explore it in more depth, but that he tried to give a sense of it within the limits of the space.

There was also an effort placed in not addressing the idea of cures, and instead considering medicine's limitations:

"… you don't get cured of PTSD, you don't necessarily… you don't get cured of two missing legs, but there's… there's ways you can progress, and carry on living, and enjoy life, but there's… back to that sort of limitation on medicine again…" (ibid.)

By acknowledging that change has happened, and yet life can continue, the *Wounded* Gallery was able to prevent a fully medical approach, instead acknowledging the social model and considering how life could be successful for people who had become disabled during the conflict, without ignoring the lasting impact of their impairments. Throughout, there is an emphasis on the agency of the disabled individual, acknowledging the impact of their injuries without focusing on pity.

The Blind School:

The opening panel of *The Blind School* exhibition sets it out as a pioneering place, explaining both the oppression that disabled people have experienced and what has been done to combat that. It does so in a way that emphasises and encourages the agency of disabled individuals, refusing any idea of pity. In this, the museum exhibition places itself clearly in support of the social model, considering how society has responded

towards disability and also thinking about how disability has shaped the physical landscape.

> "For the past 800 years, our buildings have played a vital role in the history of disabled people. From public centres to private residences, buildings are physical witnesses to the moments when disabled people have come together to learn, meet others, protest and live independently.
>
> Before the mid 20th Century, there was little support to enable disabled people to live independent lives. By complete contrast, the pioneering School for the Blind was founded here in Liverpool in 1791. As the second school of its kind in the world, it led the way in educating and empowering blind and visually impaired people. Over its 227-year history, it has changed hundreds of people's lives, and continues to do so." (Museum of Liverpool, n.d.)

This opening sets out clearly several key ideas: the importance of the agency of disabled individuals, the idea of the school as part of a wider story surrounding disability, and as part of the city's history and the history of individual lives that were affected by it.

The panels continue to set out the school's role in educating and training blind people, but were willing to consider the negatives as well as the positive impact that the school had. This can be seen within the text of the panel below (Figure 5.8).
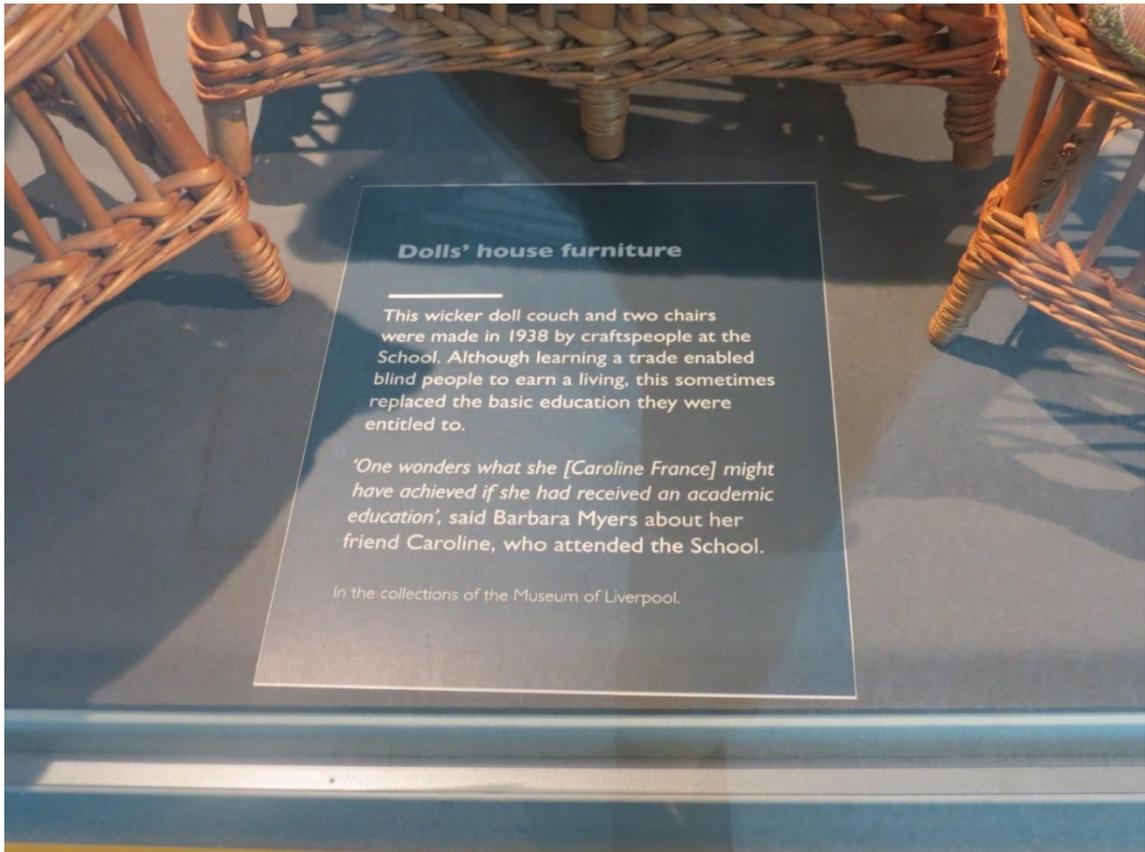
Figure 5.8: Object label from *The Blind School*, stating that learning a trade "sometimes replaced the basic education" students were entitled to, and including a quote from a friend of one of the students about the impact that it had (Photograph by Jenni Hunt)

Here the exhibition ventures beyond the celebratory model suggested by Sandell: it is presenting a more nuanced view of what was achieved, acknowledging both the positive impact that the training had, and also the restrictions it placed on the lives of its students. This ties in to Ott's (2010, p. 270) work acknowledging that addressing nuance and complexity allows work to be carried out in greater depth.

Some of the visitors at the *Blind School* exhibition were unhappy with the inclusion of these items, as Esther Fox explained:

"There was one comment about *The Blind School* exhibition saying 'Oh why do you just make us out to be basket weavers?' and um, I think they kind of missed the point. The point was that we were trying to say that these objects that were made at the blind school were actually highly sought after pieces of craft that were, you know, by today's standards you'd be selling them on Etsy. For like,

300 quid a basket, that was, you know, the point we were trying to make and so you can never account for how somebody is going to interpret something." (Fox, 2018b)

This shows how visitors bring their preconceptions and assumptions to the museum, and respond not just to what is shown, but also based on their prior thoughts and experiences. Due to social attitudes towards disability, and a negative "regime of representation" (Hall, 1997, p. 269), some visitors expect to be faced with negative representations of disability, and this can lead to them responding negatively even to more positive representations. However, encouraging audiences to see these items as valuable craft pieces reframes ideas of disabled individuals' work, attempting to address negative attitudes.

Challenging such assumptions and preconceptions is viewed as an important part of the Liverpool Museum's work of being "an inclusive museum service" (Liverpool Museums, 2018a). One piece of work that they had carried out for this aim involved examining language and disability; the *From There to Here* exhibition (2014), which worked with individuals with Down's syndrome.

"They got to make decisions about what content there was going to be in that exhibition, and how they and another group that they worked with, kind of what they wanted people to know about them, and their history. And just seeing what the exhibition meant to them, when the exhibition opened, it was incredibly powerful and I think for a lot of people just seeing an exhibition about the history of people with learning difficulties, it's hardly ever been done." (Jones, 2018)

Allowing the voices of disabled people to be heard, and to challenge the preconceptions that are made against them, is one way that museums can put their own authority behind the work being done, as will be discussed in more depth within the next chapter. Garland-Thomson (2010, p. 24) addresses how using conventional portraiture can provide "symbolic capital" and dignity to those depicted, integrating them within the space. The same kind of work is seen here. Inclusion of disabled people shown as possessing agency within museum space, and with the use of respectful language, has the potential to expand people's conceptions rather than remaining within negative stereotypes.

NDACA:

The opening panel in NDACA sets out clearly the history of the Disability Arts
Movement (DAM) and NDACA's role in preserving it:

> "In the National Disability Arts Collection and Archive Wing, you can study and
> research the story of the UK Disability Arts Movement. One of the most
> successful political arts movements in the world, the UK DAM was a Unique
> Cultural Phenomenon in which disabled people and their allies broke barriers,
> helped change the law, and made great culture and art about those struggles."
> (NDACA, n.d.)

This sets out clearly the celebratory focus of the Wing and the NDACA project, and
emphasises the agency of those who were involved within it. The sign itself (Figure 5.9)
features various disability artworks within its heading, foregrounding again the range of
artwork which the Wing records and celebrates.
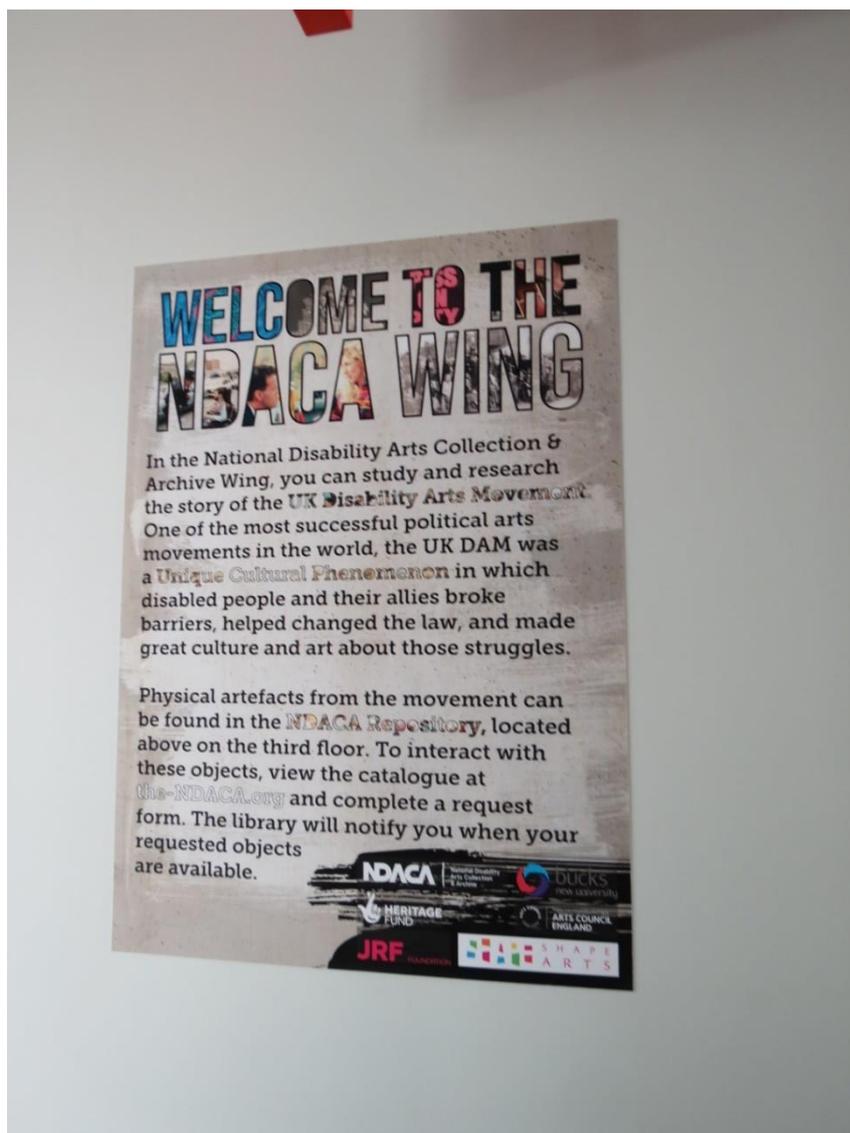
Figure 5.9: Welcome sign to the NDACA Wing (Photograph by Jenni Hunt)

This celebration of the impact of the Disability Art Movement is interwoven throughout the space, with timelines highlighting the political impact of the movement and showcasing the impact on art and theatre.

The map of the Wing (Figure 5.3) also sets out the key ideas behind the stories that are being commemorated:

> "The National Disability Arts Collection and Archive (NDACA) is preserving the heritage of the Disability Arts Movement, when disabled artists and activists used arts and culture to campaign for equal rights, express themselves with pride, and come together with a sense of shared purpose and history. As members of a political and arts-based movement, these disabled artists and their

allies fought to remove barriers and change how disabled people were perceived

by society." (NDACA, n.d.)

This panel again foregrounds and celebrates the actions of disabled individuals, before going on to discuss the centrality of accessibility to the NDACA Wing.

Here is language deeply focused on the achievement of disabled individuals, commemorating what has been gained and presenting positive information whilst emphasising agency, fitting well within Sandell's celebratory model (2005, p. 191) discussed above. The fact that the NDACA wing presents information deeply rooted within the social model is not surprising; however, the extent to which it presents this provides an interesting contrast to the other two case studies.

Comparison:

All three sites used language linked to the social model within their presentation, but what they said varied dependent upon what they are trying to achieve, with NDACA most deeply immersed in displaying disabled achievement as this is key to the underlying message of the site. All the sites use language to avoid reinforcing the range of negative stereotypes that exist around disability, and particularly to counteract any idea of pity or helplessness. Beyond this, though, they all provide the opportunity for disabled people's own voices to be heard and represented within their text, reinforcing the agency of those represented – and this is something which I will look at in more depth in the following chapter.

Aspect: External Communications

Before visitors attend an exhibition, they need to learn about it and decide whether or not it is worth their time and effort to attend. This decision is often based, at least in part, on the external communications a museum presents – its posters, advertisements and websites which seek to draw in guests and inform them about what is on offer. These external communications will have a large audience, not all of whom will attend the exhibition, and so how they represent individuals and the way they talk about them will have an impact beyond those who visit the exhibition in question.

***Wounded*:**

Wounded was advertised in a number of ways, including a poster (Figure 5.10) and a website, both of which provided key information about the exhibition.

The poster shows the location, dates, and social media handles, with text stressing the "remarkable medical innovations" of the First World War, beneath which is a black-and-white image of a man being evacuated from the trenches. Covered by a blanket, he is carried by two men, with a third walking beside – all of whom have their faces away from the camera. Beneath that is the title of the exhibition, with the O of 'Wounded' made up of two splatters resembling blood, splashes of which have spread onto the neighbouring letters. In this image, the disabled body serves a faceless prop, and the text refers to medical innovation. This medicalised view linked to an ongoing debate about the purpose of the exhibition.

As Emmens (2018) explained, there was a conflict between triumphal and nuanced approaches to the topic

> "When this exhibition [was] in its early days a very senior member of staff said, you know, 'this exhibition is going to be about the triumphs of medicine in the face of the carnage of the First World War' sort of thing, and I was sort of thinking 'it's not going to be about that', because that isn't the story. Out of war does come innovation and new ideas, but it, you know, also comes out as chaos and mistakes, and … Painful lessons learned, and rediscovering old ideas, and reapplying stuff and… you know, there's a whole range of things, so I wanted that to come out."

The question over what the focus of the exhibition would be shaped the advertising, and the overall external message, in a way that can also be seen within the website.

Figure 5.10: Poster advertising *Wounded* (Image by the Science Museum)

The website for *Wounded* again shows the image of an injured soldier on a stretcher. Although this time his body is angled towards the viewer, his face is turned away, and is therefore less clear than those of the soldiers that are around him (Figure 5.11).

Figure 5.11: Header for the *Wounded* Exhibit (Image from the Science Museum, 2018c)

The website itself begins by explaining the scale of injury, with 57,000 casualties on the first day of the Battle of the Somme, before going on to state that this created "a medical emergency of unprecedented scale and severity" (Science Museum, 2018a). It then introduces the exhibition, saying that it "commemorated the centenary of the momentous battle, and examined the huge medical and human impact of wounding during and beyond the First World War" (ibid.). Much like the text in the panels for the exhibit, the focus here is on the lasting impact of the war. Further down the page a selection of highlights are displayed, including a diorama, a wooden prosthetic leg, and a dog's collar (Figure 5.12).
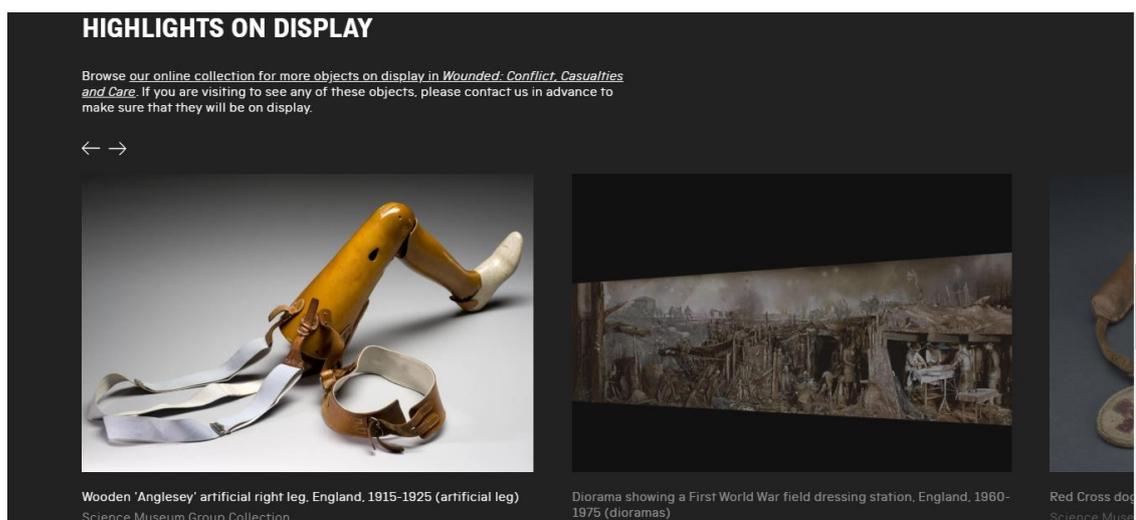
Figure 5.12: Highlights on display at the *Wounded* Exhibit (Image from the Science Museum, 2018c)

There is little text provided to explain these objects, with no information about the user of the artificial leg or the injury that they might have suffered. The advertisement is meant to encourage the viewer to visit. In presenting a leg without the person who once accompanied it, the visitor is able to stare without inhibition, to enjoy the "pleasure of unaccountable, insistent looking" (Garland-Thomson, R., 2000b, p. 349). The viewer is allowed to be intrigued, to stare at something that they would not normally be able to look at, and this can serve to attract the visitor. This idea of staring is repeated in the short video that is included, which shows men rolling up trouser legs to reveal their prosthetics, and learning to walk on prosthetic legs, as the text encourages the viewer to "discover the fate of the First World War's wounded" (Science Museum, 2018c). The viewer is being presented with the chance to learn a story not normally told, and this may intrigue them, causing them to visit.

On this particular website, disabled voices are not heard, nor are their experiences spoken about beyond the images that have been discussed. However, the text makes it clear that these voices will be heard within the exhibit:

> "*Wounded: Conflict, Casualties and Care* drew on the Science Museum's extensive First World War medical collections as well as the words of the wounded and those who cared for them to explore the remarkable medical responses and innovations catalysed by this conflict." (Science Museum, 2018a)

Here, at least, the voices of the wounded are acknowledged and prioritised.

The purpose of this website is to intrigue and attract viewers, setting out enough of an explanation of what is being presented to entice them to visit the exhibition. This is similar to the use of *The Blind School* website, but, as we shall see, quite different from the purpose of NDACA's website.

***The Blind School*:**

Unlike the black and white which dominated the advertisements for *Wounded* – a reflection of photography at the time – the external communications for *The Blind School* were full of colour. The eye-catching poster for *The Blind School* exhibition (Figure 5.13) foregrounds the image of a blind woman, Caroline France, and her guide dog. Several of Caroline's objects are held within the museum collection, she is referred

to in museum text, and the museum has previously held a small exhibit about her life. Her red coat draws the eye, and she is shown standing independently. Only the dog and the dark glasses she is wearing serve to indicate to the viewer that she is blind.
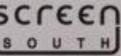
Figure 5.13: Poster for *The Blind School* exhibit (Image by the Museum of Liverpool)

The image of Caroline France was also repeated as the header for the exhibition's website (Liverpool Museums, 2018b). Beneath that was an explanation of the exhibit, setting out that Liverpool's Royal School for the Blind was "the first school for blind people in Britain and the second in the world". It then goes on to emphasise that the founder was blind, and created the school "with a number of his blind and sighted associates". By emphasising the achievement of disabled individuals, the exhibition could be seen as challenging negative stereotypes.

The website goes on to list the topic of the exhibition and what it held: "unique objects, spoken stories and a film made with visually impaired and blind students from St Vincent's School challenging people's attitudes towards blind people, past and present". That film is included on the website, alongside a trailer for the exhibit and an accessible trailer. The accessibility of both the exhibition and the museum are emphasised (Figure 5.14).
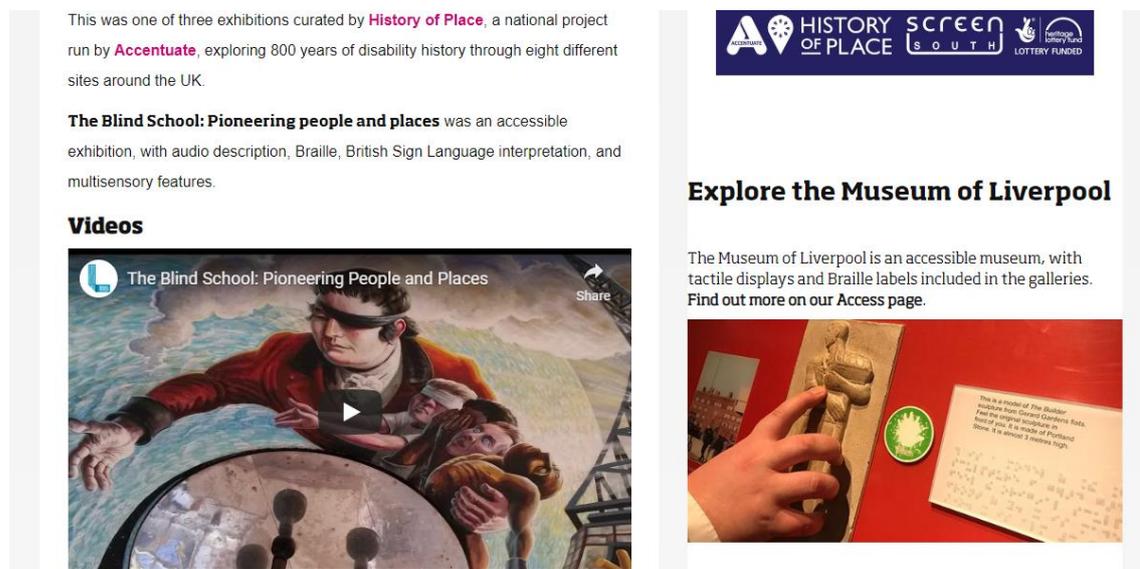
Figure 5.14: Screenshot of the website for *The Blind School* highlighting the accessibility of both the exhibition and the museum as a whole (Image from the Museum of Liverpool, 2018b)

The website also contains a copy of the audio guide, which will be discussed in further detail within the next chapter. It serves as an audio-described tour of the exhibition, including information about what is present and the layout of the exhibit, but also

including humour and emphasising how attitudes had changed over time. Featuring the audio guide on the website enables potential visitors to understand what is at the site, as well as meaning they can prepare for their visit, for example by downloading the guide to a tablet or phone if they do not wish to make use of the headsets provided at the site.

By emphasising accessibility within their advertising, the museum was able to increase the number of disabled visitors that attended the exhibition. Jones (2018) spoke about this, saying

> "We had like a film trailer which was accessible, which we'd never done before. And thinking about kind of promoting the exhibition in talking newspapers and things like that, that's definitely something I'd like to still continue for every exhibition that we do. Obviously it happened because of the type of exhibition that it was, and who we wanted to attract, but hopefully it did encourage people who had never been to the museum before to come, and hopefully enjoy the sensory elements across the rest of the museum as well. I think we definitely got an increased level of blind and visually impaired visitors. Because again, it's their history. And the young people from St. Vincent's, obviously seeing their film in the exhibition as well, the actors who did the BSL tour, and I think its hopefully made us think about using disabled artists more as well, and people telling their own histories, their own stories."

Whilst Jones acknowledged that part of the reason for this increased uptake was the content of the exhibition, she emphasised her hope that these visitors would return. If a museum hopes to widen their audience base, they need to make sure that their potential visitors are aware of their resources. Targeting disabled visitors and informing them of what the museum offers provides one way to do this, although visiting the museum may still prove a challenge. Jones (2018) raised this point when speaking of the difficulties faced by visually impaired visitors who need to cross a main road before they are able to visit the museum. Although the Museum of Liverpool is working on making their site more accessible, there are still some elements which they lack control over, and which can serve to prevent visits from disabled individuals.

NDACA:

For NDACA, the website is actually the main site, with the learning wing at Bucks New University acting as an extension to enable deeper research to be carried out. Unlike the other two websites, which served as advertisements for their exhibitions, the website at NDACA is designed to host the key information (Figure 5.15). It stores over 3,500 searchable artworks, alongside films of disabled artists talking about their work, and information about the Disability Arts Movement.
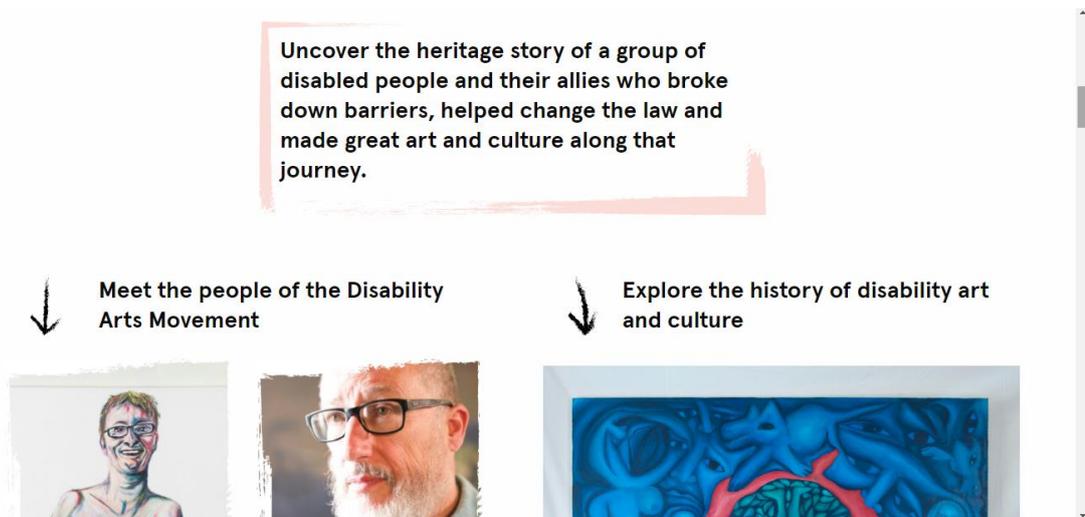
Figure 5.15: Screenshot from the NDACA website (Image from NDACA, 2019a)

The website is designed to be accessible and easy to use, setting out the history of disability art and the key figures of the movement. The tone of the website is celebratory as defined by Sandell (2005, p. 191), referring to "a group of disabled people and their allies who broke down barriers, helped change the law and made great art and culture" (NDACA, 2019a). This celebratory tone is carried on throughout the site, emphasising what has been achieved by disabled artists and allowing them to share their experiences in their own words.

There are a number of video interviews on the website, along with a range of images which can be searched through, demonstrating a variety of works. There are also key figures listed (thirty-four as of January 2020), explaining who is who in the Disability Arts Movement. The website is full of images, although little information is provided with each picture. There is also space for viewers to contribute and to take part in the NDACA project: towards the bottom of the page, beneath links to Social Media

accounts, there is a section which says "Help us grow our heritage story" with space for a message and images to be uploaded (Figure 5.16), enabling the collection to continue to expand.
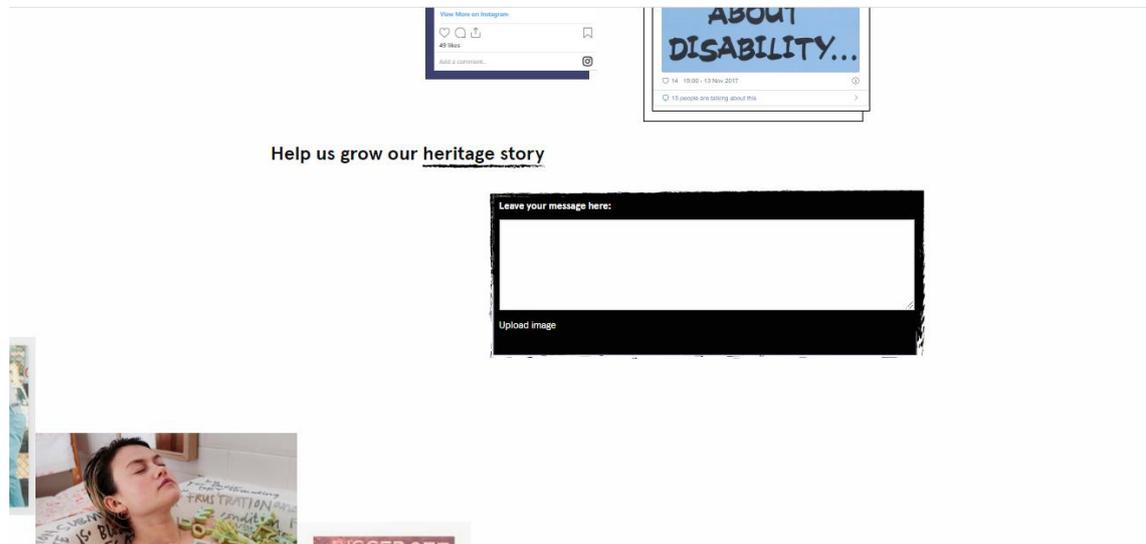
Figure 5.16: Space asking for contributions on the NDACA website (Image from NDACA, 2019a)

This space links to a point raised by Alex Cowan about the need to maintain relevance within a collection such as NDACA, stating

> "I despise what I call 'sixties archives', 'In the 1960s the music, the sex, the drugs, the fashion… was brilliant. The best it's ever gonna be and the best it ever can be,' and it's almost like it's not worth trying to equal that moment. And you have to… if you're going to make an archive about a movement and keep it interesting, and generate younger audiences, and people to keep coming, it's got to be open and inclusive, not exclusionary." (Cowan, 2019)

By allowing viewers to contribute their own experiences, NDACA is able to expand and look at the events it celebrates from new perspectives, and hopefully record new information. Of the three case studies discussed, this is the only website that enables the viewer to respond and to share their stories. This ties again to the idea that for NDACA, the website is the main focus – the main location of audience interaction. The contributions – from disabled artists, interviewees, and from website viewers – are a form of participation which will be covered in more depth within Chapter Six.

Alongside the website, NDACA has produced other forms of external communications to raise awareness of the project. These include a brochure explaining the collection, an easy-read brochure "Looking after the history of Disability Art", a booklet about "giving digital meaning to the Disability Arts Movement", fridge magnets, information about partners, and a series of postcards featuring work about disability created by disabled artists (Figure 5.17).

Figure 5.17: Photograph of postcards, booklets, leaflets and easy-read guide produced by NDACA (Image by Jenni Hunt)

Different artworks created by disabled artists feature across the collection, and the fridge magnets feature key slogans from the history of the disabled arts movement, such as "Piss on Pity" and "Not Dead Yet". These provide further ways of spreading information about NDACA's work, and highlighting the Disabled Arts Movement and the Disability Rights Movement that it ran beside. Providing an easy-read guide to the collection is significant, as it shows an attempt to make the work being done accessible to all, including those outside traditional museum audiences.

Comparison:

While both *Wounded* and *The Blind School* include images of disabled bodies on their posters, they do so in very different ways. In *Wounded* the disabled figure is a faceless lump of blankets – a strong contrast to the independent and powerful Caroline France shown in the poster for *The Blind School*, and indeed a contrast with the artworks around disability presented by NDACA. The agency and directness shown in these images links to the work carried out by Garland-Thomson, who highlights the "symbolic capital" (2010, p. 24) that can be conveyed in images which present disabled people with respect and dignity. As will be discussed within Chapter Seven, these three exhibitions were created with differing purposes in mind, and this helps to explain the reasoning behind the different presentations of disability in their external communications.

Majewski and Bunch (1998, p. 154-157) speak of three layers of access. Providing information in a range of formats goes beyond ensuring physical access, to helping disabled visitors access the content of the exhibit. Having information provided in different ways shows the curator's "commitment to make the content something to share with everyone" (ibid., p. 156). For an exhibition to be accessible, it must be possible to access it in a range of different ways, and this is reflected in the BSL translations, captioned videos and easy-read guides which are included within the sites' external communications. This allows potential viewers to know what is on offer, and to know that it is accessible to them.

Challenging Narratives

Having set out what the case study museums have presented within their exhibitions, I will now consider how they are using this to challenge the negative stereotypes which exist around disability.

The images that museums present to the world are able to challenge dominant regimes and provide counter-arguments to negative portrayals (Hall, 1997). If, however, an image is too alienating, it may serve to prevent disabled people from visiting a museum, as they fear that negative stereotypes may be replicated within. This ties to Snyder and

Mitchell's (2006) work about the cultural location of disabilities, which examined sites at which disabled individuals have been partitioned off from the rest of humankind in order to be studied and segregated, dislocating them from society and devaluing them. This is a history that some museums are beginning to engage with. By presenting the voices and stories of disabled individuals at their sites and on their websites, museums can be seen as sharing their authority rather than further repeating the dehumanisation of those portrayed.

As discussed in Chapter Three, the social model within disability studies is the idea that disability is socially constructed on top of impairment, due to "society's failure to accommodate it" (Dodd et al., 2006, p. 21). As Shakespeare (2014, p. 38) explains, "disability is a complex interaction of biological, psychological, cultural and socio-political factors" which cannot be neatly separated, and removal of barriers would not remove all of the problems a disabled individual faces, such as being in pain. However, while even with barriers removed disabled people find themselves facing difficulties that non-disabled people do not have to deal with, the barriers that society puts in place are an additional and major burden. Museums are increasingly working towards being socially purposeful, (Sandell and Dodd, 2010; Allday, 2009; Chambers, 2010). By including disability within an exhibition and focusing on the social model, the museum is able to serve as a site of encounter between visitors and disability politics (Goggins, Phillipson and Alberti, 2017).

The decision to include the social model within each exhibition was important to the curators, as can be seen within Chapter Seven. Here, however, attention moves to how the social model was actually shown within the case studies.

NDACA addresses the idea of the social model and society raising barriers clearly, speaking on the front page of the website about "disabled people and their allies who broke down barriers" (NDACA, 2019a). This focus on the social model links to the political element of their work, as they record the history of the Disability Rights Movement, where the social model was first developed (Shakespeare, 2014, p. 29). Due to this history, the social model is central to the work NDACA is doing.

While the other two case studies were less direct in their addressing of the social model, it was still present. *The Blind School* exhibition contains a film "challenging people's attitudes towards blind people, past and present" (Liverpool Museums, 2018b). The *Wounded* exhibition initially stressed a medical model – talking about the impact on the soldiers "who were left physically and mentally affected" (Science Museum, 2018a), something which perhaps arose due to the medical focus of the exhibition and the scientific focus of the site itself. However, the social model was still acknowledged, with the opening panel of the exhibit saying that "another outcome for society was a progressive shift in attitudes towards a generation of disabled veterans" (Science Museum, n.d.). This idea of challenging society's attitudes towards disability is something which is repeated multiple times within the text, including the following on a panel about returning home:

> "The very public return of these thousands of predominantly young men had profound implications for society and challenged prevailing attitudes towards wounded and disabled veterans – for the wartime period at least."
> (Science Museum, n.d.)

The panel then goes on to raise questions around funding for the newly disabled veterans, and their reliance on charity, as discussed above. Significantly, here the exhibit implicitly raises considerations about support for disability, highlighting issues with the unreliability of funding, which links to a lot of the discussion about life for people with disabilities in Britain today – in which disabled individuals who require support are considered as lazy or as scroungers (Hadley, 2016). The exhibit also talks about different attitudes to types of wounds, addressing the stigma faced and again considering the barriers society created for disabled individuals.

All three of these case studies serve to present the social model to visitors, and in doing so educate them about current concepts within the Disability Rights Movement. Having examined how the social model is used across all three case studies, I now turn my focus to the overall effect of the elements which this chapter has discussed.

Conclusion

This chapter has set out three case studies, all of which aim to present information about disability to their audience. They do this in a number of different ways; however, each of them is working to use what they are doing to begin to combat the negative stereotypes which often exist around disability.

First of all, simply being willing to show disability within these exhibitions is meaningful. Representation matters, affecting the views of both those depicted and those that interact with them. Antle's research (2004) shows how young disabled individuals can internalise negative views of disability, leading to low self-worth. Beyond this, the views and beliefs people have around disability will have a real impact on the lives of those who are disabled. As discussed above, Nario-Redmond (2010) gives an example of this, stating that when disabled individuals are not considered as parents, changing tables for infants are not made fully accessible, which affects the lives of disabled parents. With these negative views having a lasting effect on the lives of those that are disabled, it becomes important to represent disabled people, and to do so in an accurate way rather than perpetuating negative and harmful stereotypes.

This portrayal can be the celebratory representation discussed by Sandell (2005, p. 191), which focuses on the positives in a temporary exhibition, or a more pluralist view, which considers both positive and negative elements of the history being examined. Even when discussing difficult histories, however, providing space for a marginalised group serves as "a form of cultural validation or endorsement" (Sandell, 2005, p. 194) which emphasises their importance and shows that the site believes that they are worthy of discussion. Museums are seen as sites of high culture and value, and so, by depicting disabled individuals with respect and consideration, they are able to bestow value on those shown, increasing understanding.

This value is also shown not just in the representation of a particular group, but in making the space accessible to them in different ways. The provision of audio guides, braille, and tactile models assists with this. By prioritising disabled groups and ensuring that content is accessible, museums are showing them as worthy of inclusion. An example of this would be the provision of offset seating within the *Being Human*

exhibition at the Wellcome collection, which provides a degree of equality between disabled and non-disabled visitors. This enables visitors who use wheelchairs to view screens face on, rather than being expected to sit over to the side to view films. The *Being Human* exhibition also made the choice to prioritise the accessible entrance to the exhibition, again bestowing value rather than treating access as an add-on (Wellcome Collection, 2019c).

Staff at all three of the case study sites spoke of the importance of the social model when presenting disability, which again helps to challenge pre-existing stereotypes, and to alter the perception visitors hold around disability. The case studies were also all aware of the importance of allowing disabled voices to be heard, in order to tell stories in ways that privilege lived experience. This led to a plurality of voices being included within the exhibitions themselves, with all three case studies featuring co-produced sections. In the next chapter, the focus falls on these elements, their links to theories of participation, and the methods by which they were created.

Chapter Six – Collaboration and Co-Creation

Introduction

Museums are increasingly aiming to share their authority by including participatory projects within their exhibitions. These are projects which involve working with participants, often audience members or individuals from the group which is being discussed within the exhibit. These projects can take a number of different forms, from the inclusion of quotes or interviews to the collection and selection of items displayed to the creation of the exhibitions themselves. All three of the case studies discussed worked with disabled individuals in various ways to create their exhibitions and what follows is an analysis of the projects that were carried out across the different sites, examining the process of co-creation and the considerations behind it. This chapter then goes on to explore in more detail the ideas of sharing authority and acknowledging different kinds of expertise. It builds on the work in Chapter Five looking at how disability is represented in museums by focusing on how disabled voices are used to represent and examine this topic. It also goes on to consider the impact such work might have on audiences at the sites, and the potential impact on the participants themselves. This will then lead on to Chapter Seven, which examines the motivation behind the work that was carried out.

As discussed within earlier chapters, disabled people have historically often been ignored and not consulted about their lives and decisions which affect them (Snyder and Mitchell, 2006), and so being able to share their stories and choose how they are represented can be empowering (Garland-Thomson, 2000a). Such work can also benefit museums by allowing them to present visitors with information from perspectives that they previously may not have considered, providing the visitor with the chance to learn from the lived experience of those involved. Key to this is the concept of the social model, addressing disability not as individual failing but a societal issue emerging from barriers. By educating and explaining from the perspective of disabled individuals, museums may be able to challenge stereotypes and so help break down the barriers that the social model views as disabling.

Considering changing ideas of expertise and the concept of a plurality of voices, this chapter examines how museums are in some cases foregrounding lived experience, and encouraging visitors to listen to different perspectives. This focus on plurality of experience will link to the following chapter which focuses on the range of factors which drive the display of disability. Exploring how a range of voices are used will begin to unlock the motivation and intention leading to disability being presented at all within a museum context, addressing why attitudes may have changed over recent decades. By considering the factors that lead to multiple voices being heard, and discovering why they are viewed as important for museums to present, we can then examine how this motivation relates to the display of disability itself.

Role of Collaboration

Disability campaigners have long campaigned for "Nothing about us without us" – the idea that any research or work that is done on disabled individuals needs to be done for their benefit and with their agreement and participation (Oliver, 1992).

The inclusion of disabled voices within museums is part of a wider push towards including a plurality of voices within the museum context. Rather than presenting the voice of a single curator as the undeniable arbiter of truth, museums are instead increasingly encouraging a range of views, as was explored within Chapter Two. This section sets out this change and the impact it has had on the representation of both disability and the wider human experience.

Nothing About Us Without Us

Before considering the importance of participation within museums more generally, I will focus on the representation of disability, an area which often includes particular sensitivities which can make museum staff hesitant to consider representation (Dodd, J. et al., 2004) for fear of saying the wrong thing or else presenting people in a negative way. The history of disabled people is full of marginalisation, with stories only being recognised thanks to the "determined efforts of disability activists, public historians, and other scholars" (Dodd, Jones and Sandell, 2017, p. 87). With actual disabled histories suppressed, disabled individuals have been shown by a range of media as "deviant,

exotic, comical, pitiable, asexual, feminised, otherly, metaphoric, powerless, dependent, tragic and less than human" (Church, D., 2006), and museum staff have explained to other researchers their fear of perpetuating such ideas (Sandell, R., 2007). Such fear can in itself reinforce negative stereotypes, as museum staff may wish to avoid talking about the topic at hand and so make it more taboo. In order to challenge negative stereotypes, the topic needs to be faced head on – and indeed in the years following this study, there has been increased willingness to do so.

This concern around disability representation links to wider worries within the Disability Rights Movement. Research has often been carried out on disabled people, rather than working with them, in a way which has excluded them from the research process and further marginalised and oppressed disabled individuals (Hollins, 2010; Oliver 1992). The needs and wants of the disabled research subject have often been minimised, with the focus instead falling on the wishes of the researcher, who has controlled the research, benefitted from the project, and been seen as the expert and producer of knowledge. Oliver (1992) goes further in this criticism, focusing on the exploitation and compounding of oppression that disabled individuals have experienced which leads to their dehumanisation.

The disabled person in such research has been reduced to an object of curiosity, as shown within Snyder and Mitchell's *Cultural Locations of Disability* (2006). They define these locations as places disabled people are deposited, cut off from society and at odds with the wellbeing of disabled individuals. They discuss the way that disabled individuals are often continuously evaluated, with a focus on their inabilities and difficulties rather than ways to improve their lives or consideration of what they are able to do. They examine how disabled bodies are represented within the media and how such representation can often alienate individuals. Snyder and Mitchell also consider how disabled people have been isolated and studied within hospitals, with their differences treated with disdain. Such attitudes have led to a reluctance from some within the disabled community to engage with research unless it is seen to be of obvious benefit to them. Museums are at risk of becoming a similar cultural location of disability, based upon how they tell the stories they are exploring – displaying individuals for gawking (Garland-Thomson, 2009) rather than trying to open a dialogue. Later in the chapter, I will consider how museums aim to avoid falling into this trap.

The key slogan of the Disability Rights Movement, "Nothing about us without us", has focused on this idea of benefit to disabled individuals, linking to the concept of emancipatory research (Oliver, 1992). Within this model of research, rather than serving solely as the objects of study, disabled individuals are instead considered co-researchers, deserving of acknowledgement and a voice, including in shaping the aims of the project. There is increasing pressure from the Disability Rights Movement to encourage respect towards those who have lived experience of disability and to ensure that they gain from choosing to participate within the research.

Emancipatory research aims to remove the barriers that are often felt to be present between the researcher and the one that is being researched, replacing them with a meaningful relationship. Oliver (1992) picks out three key principles for emancipatory research: those of reciprocity, empowerment, and mutual benefit, gained by a transformational dialogue. In such a dialogue, the location of power is shifted away from the researcher. Instead, disabled individuals are viewed as collaborative researchers, who work with the researcher for jointly-owned outcomes which will benefit them. Such research requires reflection, and a willingness to adapt to meet the requirements of participants (Hollins, 2010). It also involves a readiness to recognise that the work being done is not politically neutral: it is being done in order to benefit a disabled group, and in doing so it takes a political stance, as was discussed within Chapter Two.

Turning to the museum context which I am concerned with, museums that aim to do emancipatory work have to move beyond being politically neutral. Instead, they have to take steps towards an activist position, which can be more contested than simply involving communities in telling their stories. Emancipatory work is going beyond the work done through participation, trying to emphasise providing benefit, focusing on human rights and involving new methods of participation and shared authority (Marstine, 2011, p. 11). This is something that can be controversial, with Dodd, Jones and Sandell (2017, p. 92) finding that museums fear alienating their audiences with representations that could be seen as "unnecessarily political, challenging or confronting". However, by looking at the Disability Rights Movement and the history

of disability, it is clear that the representation of disabled individuals is an inherently political act.

This political nature comes from the awareness from the Disability Rights Movement that disabled lives have been shaped by "a raft of disabling attitudes and barriers" (Sandell, 2019, p. 170). If museums engage with a disabled audience, examining the questions raised, there is the chance for a "more active, purposeful and socially and politically engaged role" (p. 181) as museums can host and frame the conversations that are taking place. Enabling the voices of disabled people to be heard is one way to achieve this.

If museums wish to represent their audiences, they need to engage with them in order to tell their stories. Marstine (2011) argues that "shared governance is the key to self-representation, a basic human right" (p. 12) – museums can promote social justice and engage in beneficial work, but they cannot do that when they hold onto power and ignore the voices of those whom they claim to speak for. Instead, they have to work with these groups in order to represent them, allowing those being spoken about to play a role in shaping their own representation.

The portrayal of disability and disabled narratives can have an impact both on the self-view of the disabled individual (Barnes, Mercer and Shakespeare, 1999) and on the attitudes of those around them (Reinhard, J.D., Pennycott, A. and Fellinghauer, B.A.G., 2014), leading to differing expectations and considerations. With disabled people often closed out from mainstream participation, museums have the capacity to either challenge or continue such exclusion depending upon the actions which they take.

Co-Creation and the Plurality of Voices

Having looked at the role of representation of disability, my attention now shifts to the role of participation within the museum sector. Over recent years, there have been changes in both the view of the purpose of a museum and attitudes towards visitors, and these two elements have combined to drive a vast increase in participatory work carried out across a variety of sites. Museums have traditionally styled themselves as archives of facts; however more recently this has shifted, and visitors are presented with objects

that resonate with their own lives, "tell their own stories, and reinforce their sense of community belonging" (Filene, 2017, p. 327). This has been reflected since the 1990s in a move towards a multiplicity of stories and views being represented, bringing "long-overdue public recognition to the history of minority communities" (ibid., p. 335), and serving as somewhere people can gather and explore their identities within the world (ibid., p. 341). This change in purpose has meant that museums are reaching out to different groups to share their stories, alongside showing a multiplicity of views rather than depicting a single view as telling the entirety of the truth.

Alongside this shift in purpose has been a change in attitude towards museum visitors. Museums have previously viewed visitors as passive consumers of information. However, over time attitude has shifted towards visitors being viewed as active participants (Avram and Burcea, 2016, p. 536), whose needs and desires must be considered when museums develop exhibitions and content. This change in perspective has led to a need for museums to engage with visitors and to work towards meeting their needs. One outcome of this changing view is an increasing amount of participatory work within museums, often with the aim of strengthening relationships between museums and audiences (Bunning et al., 2015). Museums are interested in becoming "user led", working with audiences "to create something together" (Govier, 2010, p. 3), in order to be "relevant to and demonstrative of today's pluralistic society" (McSweeney and Kavanagh, 2016, p. 15). Rather than a museum imposing what it believes audiences want, museums are more frequently working with audiences to create content which reflects the values of the audience and resonates with them.

By working with a range of audiences, museums are able to challenge particular narratives, acknowledging that what they present is "a past, rather than the past" (Ali and Callaghan, 2016, p. 313). Ali and Callaghan give an example of this by examining how the Birmingham Museum and Art Gallery has aimed to include and reflect the local community, providing an authoritative voice (p. 328) but also aiming to understand and work with different community groups. The work here shows that developing multi-faceted understanding can require time and patience on both sides, but it can lead to clear outcomes in which untold stories are shown to the museum's audience (p. 337). The end result is an indication that the work involved is necessary, as it is only through such work that we can achieve these benefits. Effective and sustained

change requires "a change in organisational culture and individual behaviours and practices" (Smith et al., 2012) – the staff working on these projects, and staff at all levels across the museum site, need to be fully committed in order to create a meaningful change.

This idea of challenging a particular traditional narrative is also shown in Willis' (2016) work with the National Trust at Rainham Hall, in which community engagement was used to change the view of the site. Here the focus was on putting people first and creating a positive and uniting experience that felt like "popping in to see a friend" (p. 173). This again was a long project, which reshaped the site and changed its purpose, involving people and giving a sense of ownership to a community that previously felt alienated from the history shown. The work that Willis discusses ties in with Oliver's (1992) work on emancipatory research: the actions carried out were reciprocal, with both visitors and National Trust staff contributing their time and expertise; it empowered visitors to feel more welcome within the space; and benefitted both visitors, who felt more welcome, and the National Trust, who gained increased relevance and use.

At points, museums have been passive in their approach to inclusion, focusing on audiences such as disabled people in their role as consumers (Sandell, 2019, p. 180). However, including participation enables new stories to be told, a chance to share power and responsibility and to broaden appeal (McSweeny and Kavanagh, 2016, p. 15). Rather than the museum voice dictating what is represented, effort can be made to show a wide range of perspectives and to approach topics in new ways.

Participation comes in a broad spectrum and this thesis focuses on active involvement, with a group and an institution working together for mutual benefit – participants are supported, gaining prestige and skills, while museums are empowered to tell "more engaging and powerful stories" (Sandell, McSweeny and Kavanagh, 2016, p. 596). It can foster further involvement, but also allows museums to "generate and embed plural perspectives on the objects and stories" which are presented (Bunning et al., 2015). Allowing a range of people to present objects in their own words can enable a greater degree of plurality to be shown, as multiple meanings can be brought to the fore. Embedding a range of perspectives within displays can challenge the idea that there is a

single correct understanding of objects, enabling a power shift from experts to non-experts. However this view is in itself faced with problems, and as will be discussed below sometimes the shift is between different groups of experts, some of whom have knowledge that is more highly valued than that of others.

Another more pragmatic reason for the popularity of participatory projects is the requirements of various funding bodies. For example, the Heritage Lottery Fund, otherwise known as HLF, sets participation as a key factor for funding (Heritage Lottery Fund, n.d.). It requires that

> "…all projects must achieve the 'wider range of people will be involved in heritage' outcome as a minimum, with more demanding requirements for larger projects. A requirement to have a bid accepted is that a site shows 'how more people, and different people, engage with heritage as visitors, participants in activities, or volunteers, both during your project and once it has finished'."

Of the nine outcomes that are used to decide whether a project gets funding, four are focused on participation – the wider range of people mentioned before, and also that people will have developed skills, learned about heritage, and have greater wellbeing. Therefore, any project that wishes to access HLF funding needs to be able to prove that it will involve a wider range of people, and participation projects are one way of achieving this goal. As will be shown when considering motivation, this had an impact on the work of some of the case study museums.

Other funders also expect museums to work to widen their appeal and broaden their participation, although not always as explicitly as the Heritage Lottery Fund. For example, the Wolfson Foundation sets out its expectation that a project they fund should encourage "better public engagement with and understanding of collections" (The Wolfson Foundation, n.d.) whilst the John Ellerman Foundation states its expectation that applicants show "commitment to collaborative approaches, either as the focus of the request, or at a minimum with a strong track record of partnership working" (John Ellerman Foundation, n.d.). Meanwhile, the Arts Council England (2020) strategy for 2020-2030 prioritises encouraging personal creativity, and creating culture "by and with people in their communities". Each of these cases shows that for museums seeking funding, it is important to demonstrate their ability to work collaboratively and encourage engagement with their collections, in order to meet the demands of funders.

Museums use social relevance to justify their existence, emphasising their role and value to communities (Avram and Burcea, 2016, p. 537). During a time of funding cuts, being valued by the local community can save a site from closure. Representation is ideologically important, but it can also have practical impacts which encourage museums to try and expand the groups that they collaborate with.

Kinds of Co-Creation

Having set out the importance of co-creation, especially in relation to the representation of disability, my attention turns to the varying kinds of co-creation. There are a range of ways that different voices can be represented within the museum (Simon, 2010), requiring differing degrees of commitment from staff and from participants.

Consideration of types of participation is not limited to within the world of museums. Arnstein's ladder of citizen participation (1969) examined differing levels of citizen participation within decision making, drawing out a distinction between the "empty ritual of participation, and having the real power needed to affect the outcome of the process" (p. 216). Being asked to contribute is not necessarily enough: it is important that those involved in a project are able to see that their actions influence the process and the end result.

Arnstein's work set out eight different levels of involvement within the participation process, the lowest being manipulation by elites and the highest being citizen power (p. 217). The groups were subdivided into three sections: nonparticipation, degrees of tokenism, and degrees of citizen power. In the cases Arnstein was examining, a meaningful contribution only came with the higher steps of the ladder, where the group involved shared planning and decision making, rather than simply the inclusion of a few token 'worthy' representatives or consultation where powerholders could simply go through the motions without being held to account (p. 220). When considering Arnstein's work, it is important to remember the context within which she was working – she was looking at urban renewal projects, which would have longer-term and deeper impacts on the lives of communities discussed than the work done within museums.

Arnstein emphasises the value of high-level participation, although she also acknowledges potential difficulties with full citizen control – high cost, low efficiency, lack of funding and the potential for separatism (p. 224). Bunning et al. (2015) discuss the different levels of participation that can be found within museum projects, and the benefits and challenges of these. They list four key kinds of participatory involvement:

- Consultation – Asking about audience expectations, needs and wants, and gathering knowledge.
- Contribution – Asking for content from audiences which the museum will then preserve.
- Collaboration – Open-ended work where the museum sets the plan and audience groups develop the plan and decide what is relevant.
- Co-creation – "Creating an output together", in which an audience group is given the skills and tools to create an outcome, working with staff to produce the end result.

However, unlike Arnstein's work, it is here emphasised that one kind of approach is not better than the others. All four of these methods are seen as providing benefits, both to the museum and to the participants. Which kind of collaboration is viewed as appropriate depends on the nature of the individual tasks that are being carried out, rather than a hierarchy in which co-creation is inherently the most valuable kind of participation. The difference here is based on the kind of work that it is being done, and the kinds of participation which accompany such work most successfully.

Bunning et al. and Arnstein reach different conclusions – but this is based on the context in which they were working. Arnstein was looking at citizen power in a political context, where the main focus is on the benefits for the community and the end result is decided by the process. Bunning et al.'s (2015) work with the Science Museum is different: they start at a point where the end result is already predetermined – a major gallery – and consider how "scale and ambition" can be used for meaningful participation, with the goal of creating and embedding plural perspectives and engaging with a large and diverse audience. In this latter case, rather than a total power handover, meaningful participation is produced by working on something new together. Often work done by museums – especially that which has been funded – will have an end

result already in mind. However, meaningful collaboration can still take place; this will be examined in more depth below.

Lived Experience and Expertise

The above work examines both the importance of representation to the disabled community, and the potential value of including individuals within the work done by museums. These together lead to the conclusion that work can be done with disabled individuals, that benefits both them and the sites in which they are collaborating. I will now give examples of where this has been done successfully, drawing on work done by Hollins (2010), Dodd, Jones and Sandell (2017), and others.

The nature of such work being done in museums is explored by Hollins (2010) in her examination of how the Holocaust Centre in Nottingham was able to work with young disabled people to better include disability representation in their collection and ensure disabled individuals felt that the museum was "a place for them" (p. 229). To enable full inclusion, Hollins drew on Majewski and Bunch's (1998) three tiers of access, emphasising the importance of physical and intellectual access as well as representation within the collection. Keeping this in mind, a Pioneers forum was set up with the museum, aiming to support young disabled people. The disabled individuals benefitted from gaining knowledge and skills, and were able to shape the goals and aims of the project. The museum, meanwhile, benefitted from their advice (p. 240). This example shows that it is possible for museums to represent disabled individuals in a way that provides mutually beneficial outcomes. In this way, they are applying Oliver's (1992) key principles of emancipatory research, empowering the young users in a reciprocal relationship to mutual benefit.

Snyder and Mitchell (2006) highlight the fact that disability is "embodied revelation" (p. 10). Those who live with disabilities have their own expertise. This idea is expanded upon in Dodd, Jones and Sandell's (2017) work on the idea of "Trading Zones", which can be used when exploring the disability history of a site. A trading zone is a space in which "individuals – from different backgrounds, with different expertise, specialism, or lived experience – can come together to discuss a problem or resolve an issue in a collaborative and, importantly, an equitable way" (p. 88). The focus here is the

encouragement of situations where genuinely collaborative and equitable work can be carried out. This work was initially aimed at disability stories, but is something which could also be used to work with other histories which have been underrepresented by the work of mainstream museums.

The concept of trading zones relies on museums being willing and eager to work with disabled individuals to make use of their collections. It also requires disabled individuals to share their knowledge of the lived experience of disability. Tom Shakespeare describes assumptions that all disabled individuals have insight into each other's lives as essentialist (Shakespeare, 1996, p. 107), as it presumes that all disabled people have something in common when often their experiences are very different. However, museums can still find their work "challenged, enriched and potentially transformed through engagement with disability rights activists" (Sandell, 2019, p. 169) as museums can be pushed in new directions, and to view situations in new and challenging ways. It is not that all disabled individuals view the world in the same way and have shared experiences, but that their experiences and world views differ from that of non-disabled individuals in ways that can challenge traditional ideas.

Museums often have large collections that they are unaware of the significance of, and disabled people can help fill in gaps in information, with their accounts exploring "the diverse experiences of disabled people themselves and in ways that challenge the boundaries imposed by purely medicalised ways of seeing" (Dodd, Jones and Sandell, 2017, p. 91). Trading zones are temporary collaborations of different groups, with museums providing their expertise in "display, interpretation and promotion of collections", whilst disabled people "have the expertise, language and experience through which museums can frame these collections", providing nuance (p. 94). Such collaboration aims to readdress the power imbalance that has often been created within museums, as well as creating a richer view of history, as both sets of experts work together for a shared goal, valuing both perspectives. Such work can increase plurality of voices and meanings (Bunning et al., 2015), including a range of valued views.

Working using the trading zone method aims to bring about a range of benefits – political, practical, and ethical (Dodd, Jones and Sandell, 2017, p. 95). Despite this, the process is time-consuming, as it requires collaboration over several meetings and the

building of trust. However, the nine case study museums discussed by Dodd, Jones and Sandell found a positive response from their audiences, alongside linking to broader issues of social justice which the case study museums within their work were eager to involve themselves with. Trading zones meet Oliver's (1992) requirements for emancipatory research, aiming to empower and benefit individuals on both sides.

The National Trust (2020) has developed its own spectrum for participation, which is shown below in Figure 6.1. This aimed to consider how its sites could work with visitors in order to share control and allow substantial participation. The spectrum was developed not simply for academic interest, but to guide sites in considering ways that they can work with their audiences and different groups in order to develop their offerings. As will be shown, the different sites fell on various points on this spectrum, varying dependent upon which elements of the case study were considered.
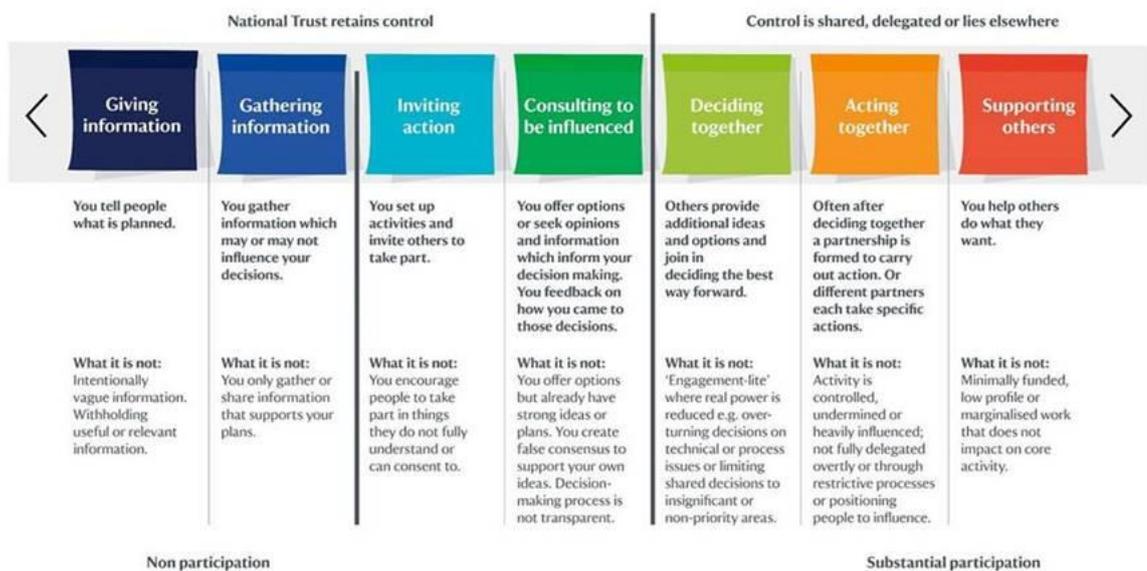
Figure 6.1: National Trust Spectrum of Participation (National Trust, Internal Document, 2020)

Co-creation can strengthen relationships between museums and their audiences (Bunning et al., 2015), bringing in outside voices and imbuing them with the authority discussed above. If museums are keen to address inequality, the shift in power from the expert to a collaborative group within the trading zone method offers one potential way

forwards. It also shows an awareness of the agency of disabled individuals presently and in the past as groups share their expertise and hopefully uncover new ideas and methods of representation. Over time a number of different spectrums of participation have been proposed, as have been discussed above. The trading zone would fall on partnership rung of Arnstein's (1969) ladder: the community is involved in discussion on an equal footing but does not have total control over what is achieved. The work is run by the museum, with both sides bringing what they can to the table, in order to create a stronger end result than could be achieved by either group acting alone.

Purpose and Experience

Both museum workers and collaborative partners have different skills, and by getting participants to share "relevant experiences, expertise and insight" (Bunning et al., 2015) museums are able to gain a personal perspective. Bunning et al. found that museum staff were initially sceptical and anxious around collaborative projects, willing to acknowledge the possibilities but concerned about the time commitment and questions over quality. When the Science Museum provided training and skill workshops, and ensuring equal partnership between staff and participants, museum evaluation of the project found that there was greater appreciation for the approach and a higher confidence in the end result. The participants reported a "sense of enjoyment and pride… emphasising a sense of ownership and responsibility for the finished products". Despite this, it was reported that not all plans could be realised, and not all of those participating felt they achieved benefits, finding that the project was not a good match to their skills and interests (Bunning et al., 2015). It therefore seems that museums need to ensure that they are communicating well with participants from the very start of their work to ensure that expectations on both sides are managed and benefits achieved for all those involved.

As has been seen, there is an increasing movement towards the inclusion of a range of voices within museum exhibitions. Such work is taking part to empower, and to make museums more representative of, their audiences, alongside acknowledging a range of different kinds of expertise. By working alongside disabled individuals, museums are able to reciprocate, sharing knowledge and showing respect, ensuring that both sides are able to benefit. The demands of many within disability studies, summed up in the

catchphrase "Nothing about us without us" (Oliver, 1992), fit well with the desire from museum studies to work with their audiences. Including disabled people in the development of relevant displays will benefit both groups, creating innovative final results whilst acknowledging the lived experience of those participating.

Types of Co-Creation in the Case Studies

Having considered the motivation and impacts of the growing use of co-creation, I now turn my attention to my case studies, to consider how co-creation has taken place across the three sites.

There are a number of different ways that this has been done, with each site using a range of methods. Some of the objects which were chosen to be displayed have been created by disabled people, and quotes from disabled people can be found within multiple sites. Disabled people have also been involved in the collection of materials, both contributing to the main collection, as has taken place within NDACA, and for specific exhibitions created with disabled people, as seen in the Science Museum and the Museum of Liverpool. There are elements of co-created display, and work carried out by disabled staff members – both permanent employees, and hired consultants. Finally, disabled individuals have been the stars of audio guides and films across the sites, with their own words heard in galleries and on the websites.

As discussed above, it is not that one process or form of participation is more valuable than others (Bunning et al., 2015; Simon, 2010), but rather that a range of types of participation have value. Both museum workers and disabled individuals have experience and talents, and through working together these assets can be explored and presented to an audience who would otherwise be unaware of the issues that are being raised (Dodd, Jones and Sandell, 2017, p. 91). Rather than presenting any particular form of co-curation as superior, my aim here is to explore how and why each method is used, and to consider the results that follow from them. Different kinds of participation are undertaken to achieve different goals, but all increase representation, empowering the disabled individuals who are involved alongside informing those who witness these

projects. This informing will hopefully enable negative stereotypes to be challenged, and in doing so help to change people's views towards disability.

Exhibition Objects

Perhaps one of the most obvious, but also most passive, methods of including disabled people within an exhibition is through the objects that are displayed. Objects created by disabled people provide the exhibition space with an acknowledgement of the existence and creativity of disabled people. The creators have not necessarily been consulted in this, but they formed the objects which have now ended up on display, and therefore in a way have participated in the museum's work.

As the exhibitions chosen for this thesis were ones which were focused on disabled experiences, it is unsurprising that all of them contained objects produced by disabled individuals. The Science Museum featured newspapers created by people being treated for shellshock, and poems written by famous war poets. The artwork at NDACA was all created by disabled artists, in response to the Disability Rights Movement, and Liverpool's exhibition featured examples of the crafts that were produced by students at the school (Figure 6.2). As discussed above, the panel beside these objects explained how such craftwork could replace the basic education that the students were entitled to, highlighting both the skill of these creations, and the attitudes they embodied.

Figure 6.2: Dollhouse furniture produced by students shown at *The Blind School* (Photograph by Jenni Hunt)

Even this simplest method of simply gathering work without input from the producers came with difficulties, however.

> "There was one comment about the *Pioneering People and Places* exhibition
> saying 'Oh why do you just make us out to be basket weavers?'" (Fox, 2018b)

Although the work was being displayed in order to acknowledge the achievement and talent of pupils at the school, and also their experiences, these objects were still linked by some visitors to negative stereotypes which they had experienced elsewhere.

NDACA, which focuses on collecting more recent artwork, faced issues over the identity of the individuals involved – both because they were not always able to contact the creator, as the individual was unknown, and because the artists did not always currently identify as disabled. The project therefore based their decisions of whether to include work on whether they felt it should be seen within the movement. Hevey (2018)

spoke of one occasion where a woman addressed him during a talk, explaining the work he had shown belonged to her.

> "I was explaining the rights strategy, and I said 'oh we couldn't clear all the rights so if we felt it intended to be seen in the movement we copied it', and this woman just put her hand up and said 'well funny enough you've just shown my work'. And I could have been sick. I thought 'Oh my God'. She said 'I hope you've got a good lawyer', and I went 'Uh…' and she goes 'I'm only joking', and she was quite honoured to be in the audience, and suddenly see her work up there, and I said to her 'do you think that's right?' and she goes 'yeah, absolutely, keep doing it', so that's how we do that."

In that case, the use of artwork without consent ended up being accepted by the original artist. However, there is always a risk that this will not be the case.

Another problem faced by NDACA was questions around identity.

> "Some people are disabled, some people are artists, some people are disabled artists, some people are artists with disabilities, some people are artists and want no mention of their disability at all, to colour their work… and working out where person x or person y fitted in that continuum, that was the most trouble I ever got into. Because people have very different opinions about where they are, and what they are, and some people… their disability was – their artwork's thick with their own condition, and it was all about that. And other people it's not, and they're quite offended if you say 'you're part of the Disability Arts Movement', because they were, but now they've moved on or they've decided they're artists, not disabled artists." (Cowan, 2019)

Without input from the individual whose work is represented, the site was unsure how to best classify them. In this way, having a lack of communication with the creators of objects was clearly unideal – although sometimes necessary, when creators are unknown or deceased. However, all three sites also had much more active participation with object creators and disabled individuals.

Collection of Materials

One way of having more participation is by involving disabled people in the collection of exhibition objects. Individuals will often have objects that they have used or created, and which they may be willing to donate to a museum – an example of this would be a recent (2019) appeal by the Wellcome collection for used prosthetics and their stories to go into their new *Being Human* gallery.

Of the three case studies, NDACA was the one that was most driven by donations and contributions from disabled individuals. As well as collecting objects, their aim was also to collect individuals' stories and experiences, with Alex Cowan (2019) explaining

> "We identified some depositors, but lots of depositors came forwards, and because we've been so strongly story-driven, narrative-driven, the HLF did not want boxes and tonnes of documents and boxes, they wanted stories. Part of the process has been sitting down with individuals, obviously informed by pre-interview research, and hearing their story, and then trying to identify objects or things they've kept to tell that story, and to communicate that [for NDACA's use]."

Whilst the objects are key to allowing the archive to tell particular stories, those stories in themselves are of importance and are also gathered by the site. The stories are not just used for categorisation and cataloguing of the collection, but also for videos and the labels for the items, as will be discussed below.

The Museum of Liverpool received donated items from the local school for the blind for their handling objects, and disabled people were consulted on the items to be included. This could mean highlighting objects that would otherwise have been ignored, as in this example:

> "The long cane, for them that was an important object. We hadn't really realised the relevance and importance for them, so that was important, because that was an important story that came out, that we would have probably overlooked without that first-hand sort of asking those blind and visually impaired people."
> (Fox, 2018a)

Working with and consulting a range of people with lived experience of disability helped the museum select objects that were actually significant to their lives.

Jones (2018) explained the benefits she found from working with the volunteers, saying

> "It was useful for me to meet the volunteers and see how they reacted to the objects in our collection, and of course I learned more about the objects in our collection. There weren't any blind volunteers as part of the project, but through meeting other blind people connected with the exhibition it was really interesting to see their reaction to some of our objects and sort of tell me more about them. So that was really useful and that was obviously something I've recorded and can be used in the future."

Working with volunteers enabled her to unlock new information about objects and to identify key stories, which enhances what the museum is able to provide. This was also seen in a sister exhibition: *Without Walls: Disability and Innovation in Building Design,* which was also a part of the History of Place Project. It was held in the V&A (2018), and displayed paint swatches among the objects shown, representing the freedom of a disabled individual to choose the appearance of their living areas for the first time having left an institution. Getting disabled people's input on the objects enabled stories like these to be uncovered.

Like NDACA, the Museum of Liverpool has also commissioned work in response to other items in their collection. Jones (2018) spoke about "peopling the city", taking a large cityscape and working with different groups to show representations of themselves next to the image – a contrast to the often people-less galleries shown in museum design, which can limit access due to lack of consideration (MacLeod, 2018, p. 15). By working with disabled individuals and collecting from them, disabled bodies can be presented as part of the landscape of an area.

Although the Science Museum did work with disabled individuals to expand its collections, this was as part of the co-created display I will discuss in more depth further on in this chapter, and therefore there is little more to say about that site here.

All three sites worked with disabled groups to gather their items, using the contribution method of participation that Bunning et al. (2015) set out. Items were gathered from the communities by the museum, but in the cases discussed their input was restricted to

deciding what was seen as worthy of inclusion after the key topics had already been chosen and having their knowledge gathered about the items.

Quotations and Labels

Disabled individuals did not just have an input on the objects that ended up on display. In all three cases, their words were also included within the exhibitions, on the walls and on object labels. This exposed the visitor to the voices of disabled people, their thoughts and feelings in their own words. Presenting information in this way was seen by some as important for conveying accurately what was being shown.

> "I've encouraged people to… use the language that they would use, not my language, what do I know? I am another cataloguer sitting in a room, cataloguing stuff I know a bit about but not that I know everything about, and given that I have direct access to these people that have created these objects and ephemera, why wouldn't I want to use their description?" (Cowan, 2019)

Here Cowan (from NDACA) explains his motivations for using the exact phrasing that the donors would use, because he feels that their lived experience has enabled them to better explain the purpose of the items than his own description and would provide a more meaningful record. He rejects other previous classifications, saying

> "I mean in terms of letting disabled people represent themselves, I've tried to use – I've been very much aware as I've been writing the catalogue that there isn't a taxonomy or classification system, that's available off the shelf, that I would be comfortable using. Even the ones like the social history… there's stuff on the website but it's uh… a social history classification, and disability is still medical within that classification, I mean it's included… if I was to go to the Wellcome Trust and look at the terminology they've used for classification, I would find um… primarily a medical model." (Cowan, 2019)

As the entire project at NDACA focused upon the social model, this had to be rejected, and a new method was instead used, created from the words of donors to the site.

Using the words of those with lived experience can add depth and understanding to the experience of visitors. Both the Science Museum and the Museum of Liverpool included quotes from disabled individuals on the walls of the museum, explaining their experiences. In Figure 6.3 we can see how quotes from disabled individuals were used

to challenge stereotypes – by having a direct quote and drawing on someone's experience, this idea is brought more vividly to life.
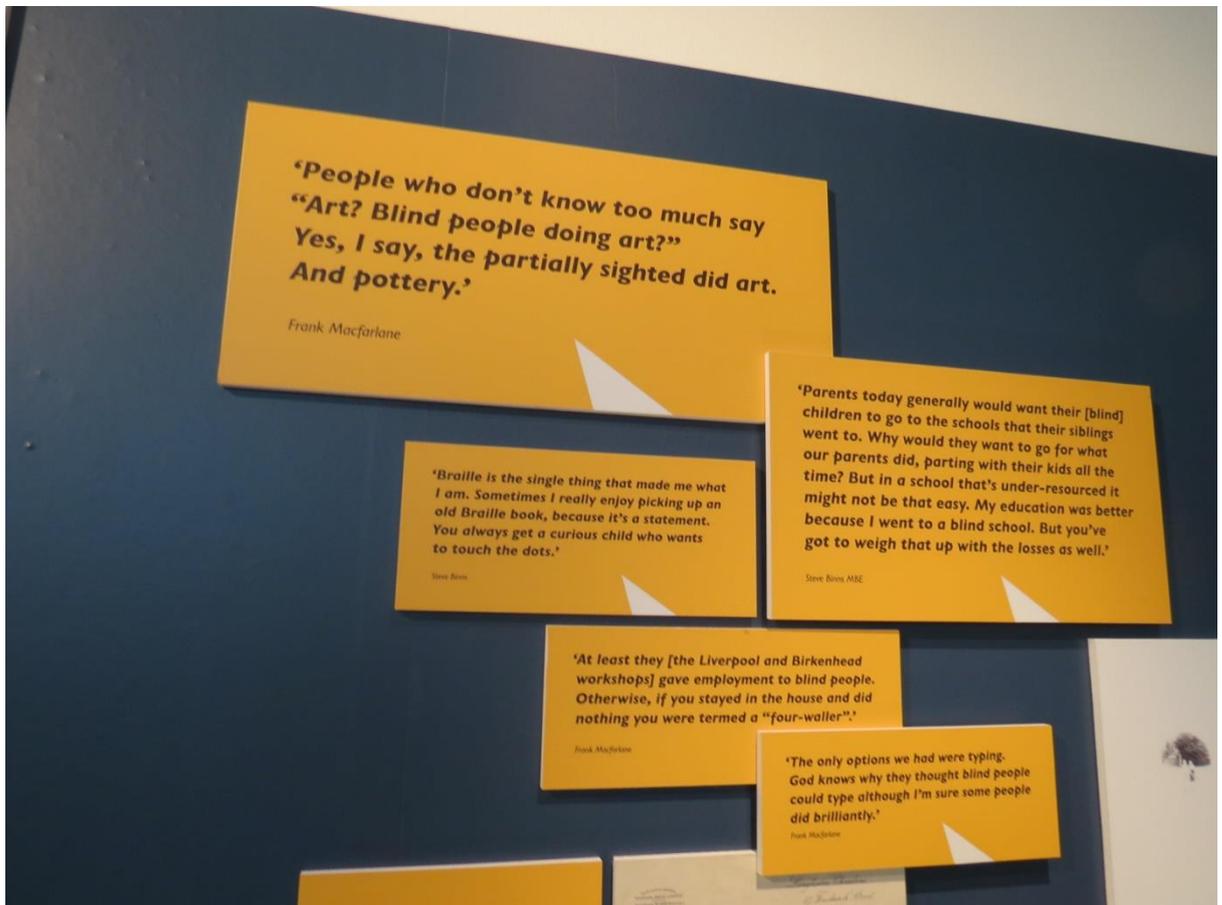
Figure 6.3: Quotes on the wall at the Museum of Liverpool (Photograph by Jenni Hunt)

Allowing an experience to be put in a disabled individual's own words appeals to the plurality of voice discussed earlier in the chapter. One individual weighs up the positives and negatives of the school, whilst another considers his success in art alongside his difficulties in typing. Direct quotes challenge stereotypes, and bring an individual's experiences more directly to the audience.

This can also be seen within the *Being Human* gallery at the Wellcome Collection, where labels were designed to have space for comments from visitors or contributors (Figure 6.4).
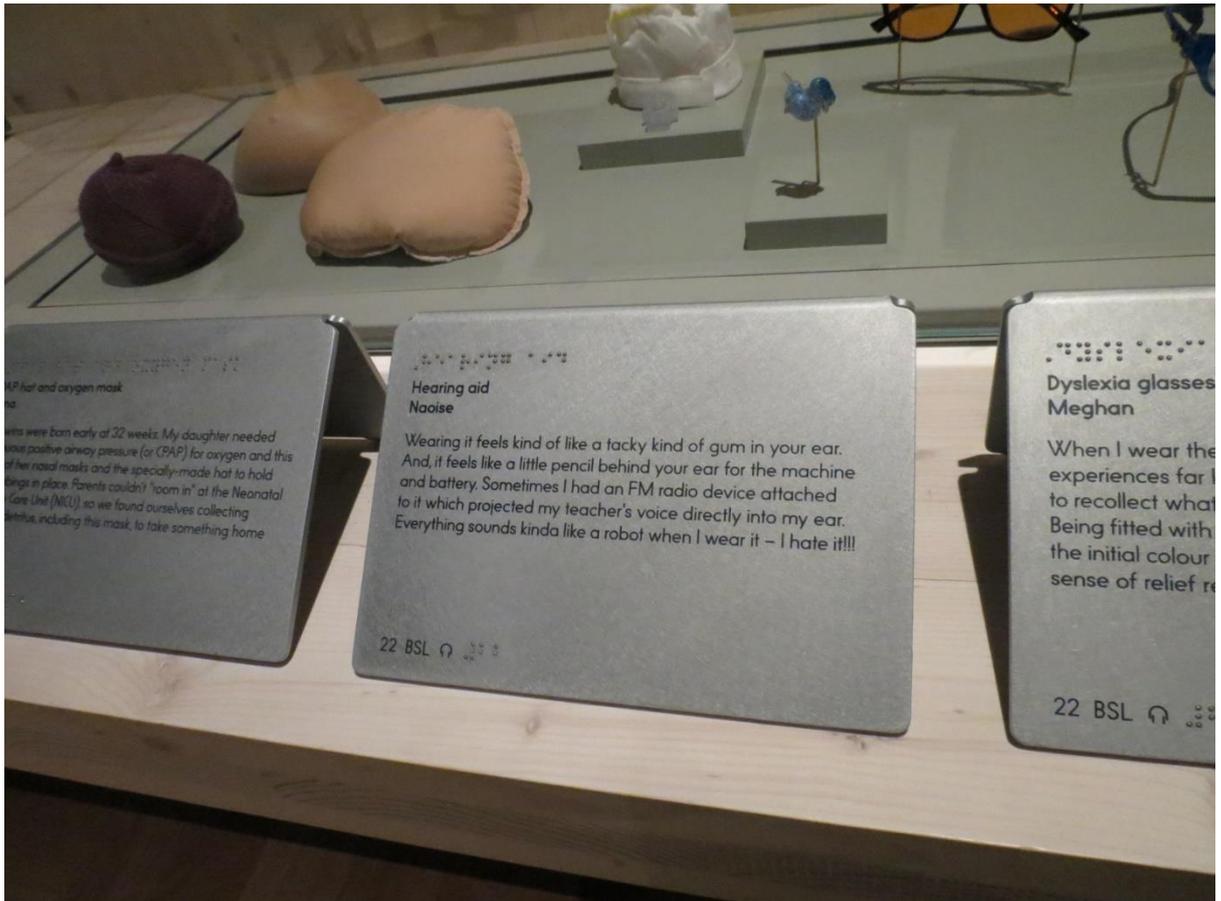
Figure 6.4: Label in the *Being Human* gallery (Photograph by Jenni Hunt)

Rather than a traditional explanation of what a hearing aid is, the audience is presented with an explanation of what one feels like to wear and use. This experience could not be conveyed with a simple description of the object as it is more emotive, drawing on the experience of using it as part of everyday life and in doing so prioritising the lived experience of the user rather than the science behind its development.

Using direct quotes can also challenge audiences. The Museum of Liverpool has done this in other projects, such as the *From There to Here* exhibition (2014), which was co-created with a group of actors with Down's syndrome. That exhibition will be discussed in more depth later, however for now I wished to focus on one element: the inclusion of language that could be seen as offensive.

> "We included language used in the past that is unacceptable now, put really high and large on the wall, but also got the guys to explain why it shouldn't be used and what it means to them, so it was really powerful in that respect as well."
> (Jones, 2018)

Jones felt that using the experience of people who had been subjected to stereotypes was effective in making people reconsider what disabled people could achieve and getting them to think about the kind of language that they would use, by empowering the individual to explain the impact that it had upon them.

In these cases, the identified words of an individual are used to focus in on their own personal experience of disability, and to convey that to the audience. Participants' words were treated slightly differently by the Science Museum, who wished to show the "anonymous individual" (Emmens, 2020). Due to the time that had passed since the First World War and the sheer scale of it, Emmens chose to present "a display where individual faces remained largely un-named, and names, where they appeared [were]… largely 'un-faced'". With a few exceptions (such as one man wounded by mustard gas, whose photograph was provided by a relative who wanted him identified), the objects used were not matched with names, and quotes were not accompanied by images.

Rather than the experience of an individual, the quotes used were instead intended to represent the experience of the masses, similar to rows of graves.

> "If you've got something on a massive scale, like the First World War, I think there is something. I mean I have… I don't know if you have, but I've been out several times to the battlefields and the cemeteries and stuff, and there is… I mean when you stand in front of an individual grave you know, there is something, you've got a name, and some sense that there is an individual, which is very powerful, but there is obviously something very powerful in that mass of… anonymous graves, because you can't read them all, or seeing row upon row of unknown soldier type stuff. Um… and I just thought that this… by not… picking on sort of 'Joe Smith and he's lost his leg on the Somme and this is what happened to him' type stuff, but rather taking a step back and anonymising almost everything, there were certain things – there was an apron on display, a nursing apron on display and we know who wore it, and we know where they were, but in the end I decided I'm not gonna tell that story, I just want it there to represent a nurse… we don't need to know who she was sort of thing."
> (Emmens, 2018)

The anonymity wasn't an accident, but was instead an intentional way of trying to represent the scale of injury that was being discussed rather than tell personal stories.

This concept is repeated within the Public Health element of the Medicine Galleries within the Science Museum

> "…because it's to do with medicine and populations, because it's public health, there are a few individuals in there but a lot of it is that sort of zooming back and looking at cities and you know, things on a bigger scale. And having lots of objects that are sort of… on their own they're sort of a vaccinator, quite personal, but are produced in masses, because they're to you know do a mass job, so I'm not interested in one person's vaccination story particularly, I'm interested in that whole… you know the sort of huge funded programmes that happen in India or something like that to deal with this thing… and the interest there is the mass rather than the individual." (ibid.)

However, within these galleries, similarly to *Wounded*, there are participatory projects which enable the voice of participants to be heard. In *Wounded*, the presentation of more recent conflicts was very different from this intentional anonymity, as will be discussed below.

Audio Guides and Videos

There were other elements of the exhibits where disabled people collaborated with museum staff, such as the development of audio guides and the creation of videos. This work took place at different scales across the three sites.

A number of oral history films were created for NDACA, placed centrally within their website and with one featured at the very top of the homepage. This allowed the artists behind some of the key works to express themselves in their own words and to tell their stories. NDACA also aims to serve as an archive to preserve what has been lost, with Hevey (2018) discussing the challenge and shock of collecting stories from black and working-class artists, many of whom have passed away. This is backed up by Cowan (2019):

> "There's just… an opportunity to tell a story. I mean it's a sad thing to say, but since I've been working on the collection six potential depositors or depositors

have passed away. So you capture this history now, or it could be argued you

don't capture it at all, because you don't have access to the… original

practitioners."

One of the artists featured in the videos, Katherine Araniello, passed away before the

NDACA wing itself opened. The videos therefore serve as a record of lives lost, and a

chance for the voices of those who have passed to still be heard.

The voices of disabled individuals played a very different role within the Museum of

Liverpool's exhibition. Rather than a simple description, the audio was "a conversation"

(Jones, 2018) between two disabled actors. The actors presented the information in a

fun way – while it still described the layout of the exhibition, the actors took on the

personas of various historical figures, explaining the historical background to the site,

the use of certain terminology (such as the fact "asylum" meant sanctuary), and setting

out the social model and change of attitudes over time. This creative use of audio was

something that the museum was keen to continue, as Jones explained.

"Audio guides that weren't necessarily just 'this is here' but rather it's giving

you content about the exhibition. I think that'd be something that I'd definitely

want to develop more." (Jones, 2018)

Because of the subject of the exhibition, the museum was preparing to have a higher

number of blind and partially sighted visitors, and so embedded accessibility to a

greater extent. Seeing this success and the interest people had towards the audio

description, which provided another narrative to the exhibition, led Jones to want to

continue this additional layering within future work.

As well as the use of audio description, there were also oral history interviews in the

exhibition. Alongside being shown in the exhibition, and quotes being taken from them

for display on the exhibition walls, a video of the interviews was created which was

shown on the website (Figure 6.5).
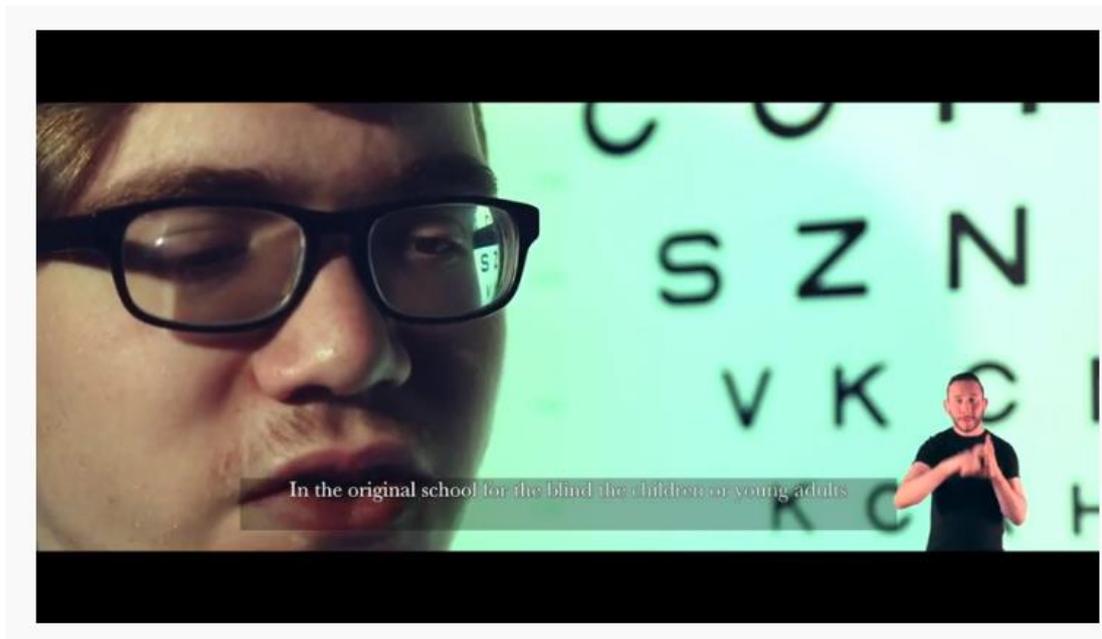
Figure 6.5: Still from *Visions: A History of the Royal School for the Blind*, featured in *The Blind School* exhibition (Liverpool, n.d.)

The film was "a big part of the exhibition, and the idea of the film was kind of to challenge people's preconceptions of their identity and of the assumptions around disabled people" (Jones, 2018). Within it, three students of a modern blind school compared their own experiences to those who attended the historic school, acknowledging the loneliness often felt and comparing it to their own frequent trips home, with a current female pupil saying "I can plan my future here. I just remember being so happy that I'd had the opportunity to become a new person". By using the voices of disabled people in this way, the museum is able to show a more nuanced view of the students' experiences, acknowledging both the positive and negative elements of the schools both past and present.

Within the Science Museum, an active decision was made not to include videos or oral histories within the main exhibition, using it only for the co-created section which will be discussed shortly. The reason for this was that the curator was concerned about the quality of the film serving to reinforce the idea of the war as "fought in silence by people in black and white in jerky print film" (Emmens, 2018). Whilst interviews recorded later did not have this problem, there was concern about the age of the soldiers at the time when they were recorded.

"There's some great oral histories told by people but it sounds… like an old man talking, I wanted to try and break down that barrier that's… that would make people unable to relate to the people that this was affecting if you see what I mean… you know, in my head really I have to stop myself [thinking]… you know, First World War Veterans are old men. But they were once twenty years old, when they were injured, so trying to sort of overcome that." (ibid.)

Rather than include videos which were shot a long time after the conflict itself, or which dated from the time but would look unclear to a modern audience, the decision was made to instead use the quotes and photographs which I have considered above. This meant that for much of the exhibition, there was little in the way of film shown. The only film which showed disabled individuals in the main body of the exhibition was a two-minute clip which was captioned:

"Rehabilitation

Hundreds of thousands of men returned home mentally and physically scarred.

Occupational therapy and employment training provided the necessary skills to help the wounded rejoin the workforce. Sporting activities were a way of regaining masculinity." (Science Museum, n.d.)

It showed men relearning how to walk and taking part in sports and occupational therapy. This ties into Snyder and Mitchell's 2006 work which examines how disabled bodies have been used as objects of curiosity, as this was a film created at the time to show the therapy being undertaken in the hospitals. There were no responses from the people depicted, and nothing to identify who they were – very different from the film in the co-created project in the next section.

Emmens explained the distinction between the approach within *Wounded* and that taken to Thalidomide within the Medicine Galleries.

"We're in close conversation with the people affected, telling some of their story as well… which if there were surviving veterans of the First World War, I probably would have done, but… because there are surviving veterans from Afghanistan, that's what we did do. So I think you know… it's the obvious thing

> to do, if you're dealing with subjects… or an exhibition that touches on disability, then… you want to work with disabled people." (Emmens, 2018)

In this quote, Emmens acknowledges the importance of working with disabled individuals, whilst also explaining why he didn't feel it appropriate for the main body of the exhibition.

Across all the sites, video and audio were used to show disabled individuals. At some points this was used to add other layers to the narrative, whilst in other cases it was used to reinforce the story told by objects and words. The reasons behind the creation of the films and audio differed, but served to provide another way to include the voices of disabled people within the exhibitions.

Co-Created Display

Having examined the contributions made by disabled people to various elements of the collections, my focus now turns to what is perhaps the most striking method of collaboration: displays that have been created by the cooperation of disabled individuals and museum staff.

The entirety of the work done by the Museum of Liverpool was created in collaboration with Accentuate, as part of the History of Place project. Accentuate is a charity which "challenges perceptions of disability by providing life changing opportunities for disabled people to participate and lead within the cultural sector" (Accentuate, 2020). Esther Fox, who is head of Accentuate and uses a wheelchair, was involved in the project and explained that she took a lead role around exhibitions "because I just felt it was really important that disabled people's voices were heard in the narrative as well" (Fox, 2018a). Alongside her own experience, disabled people were consulted at all three History of Place sites, and a digital game was created with pupils from a local school, which included students with disabilities.

The Museum of Liverpool has been involved in a number of other co-created projects working with disabled individuals. The *From There to Here* exhibition (2014) worked with actors who have Down's syndrome, displaying their art and creating guided tours. This work was important to the museum, as Jones (2018) explained.

> "I think a lot of people just assume that all people with Down's syndrome or learning difficulties are the same, but seeing these fantastic objects which reflect their personality so strongly, I think it really challenged people and made them see it differently, so the guys also did guided tours of the exhibition, in Victorian costume because they're actors, and so they explained about how people in the past who were in asylums and institutions about their lives, but they act it out, so it's really accessible for lots of different people as well."

Working with disabled individuals in this way allowed the museum to challenge stereotypes and expectations, and this is something that they have expressed a desire to continue doing in the future, with further collaborations planned.

NDACA is a disability led project, "all about disabled people's point of view" (Hevey, 2018), with over half of the staff involved in the project identifying as disabled, and the majority of those interviewed for the short films also having a disability. Hevey, the project director of NDACA, spoke of the way his epilepsy has shaped his life, both because of barriers faced and also the opportunities he found, such as becoming involved in the Disability Rights Movement. Based somewhat on his own experiences, Hevey spoke of the project being "essentially… about disabled empowerment", considering intersectional elements such as poverty which interact with disability. The interviews carried out with disabled individuals, and how their words were used by NDACA, have already been discussed above. As disabled staff were involved throughout, in a way the entirety of the project was co-created, blurring the lines between disabled participants and museum staff.

Working within a disabled community also takes place within Bethlem Museum of the Mind, which is embedded in the grounds of the current Bethlem Royal Hospital. Here, artwork by current patients is displayed alongside historic artwork and a display about the history of mental health treatment (Bethlem Museum of the Mind, 2018). With patients involved in the research at the museum and the creation of labels for their work, Bethlem Museum is uniquely positioned to combine the historic treatment of disabled people with their current empowerment. Such co-creation shows the possibility of long-term collaboration between a disabled group and a museum sharing their story, similar to what is seen within NDACA.

Meanwhile, a large amount of the Science Museum's exhibition was presented without any co-creation. This was due to the time period examined by the exhibition, and the quality and age of records, as has been discussed in more detail above. However, the final section of the exhibition, which compared similarities and differences between historic and modern conflict, did contain an in-depth participation project. The introduction to the section spoke of "similarities in the types of wounds being received, in the medical battles to save life on the front line and in the experiences of survivors living with their wounds today" (Science Museum, n.d.). Alongside examining modern equipment used to treat the injured, "Wounded Today" contained a participation project carried out in combination with the Combat Stress charity to look at the experience of modern soldiers and the impact of conflict on their lives.

There were two sections within this area: "Not all wounds are visible", a seven-minute long film in which five veterans reflected on personal experiences with PTSD, and a case titled "Living with PTSD". (Figure 6.6).

Figure 6.6: Image of the "Living with PTSD" case within the *Wounded* exhibition
(Photograph by Jenni Hunt)

The explanatory label for the case read as follows:

> "The objects and labels in this case were selected and written by a small group
> of British military veterans from recent conflicts, who have all been diagnosed
> with post traumatic stress disorder (PTSD). Through their personal choices of
> objects and words they hope to give an insight into the experience of living with
> this condition, which they believe is poorly understood." (Science Museum, n.d.)

The labels were then created by the veterans, explaining the personal significance
behind these items and what they represented for them (Figure 6.7).

2. Shrapnel

'I found this piece of shrapnel in my vehicle after an IED [improvised explosive device] strike and took it as a memento. I find it strange that we got hit by metal, but the metal of the vehicle also protected my life. I often wonder about who made the bomb. What did they look like, how old were they?'

Lewis, tour: Herrick XI, 2009
Object no: L2016-2100

3. Ripped T-shirt and para beret

'This T-shirt was wrapped round my weapon to keep it clean, when the vehicle it was in was hit by an IED [improvised explosive device]. Everyone walked away, but my T-shirt was ripped through with shrapnel. This T-shirt makes me feel ashamed that I'm relatively OK, because most of the friends who never come back didn't want to be there. I did. The beret reminds me of that pride. I wanted war, I wanted glory, I wanted to be awesome.'

J O-C, tour: Herrick IV and VI, 2006 and 2007
Object no: L2016-2098-9

4. Operational Service Medal

'Usually medals are handed out during a parade, but mine was casually passed to me through a crack in the door while I was having a smoke. I was fighting for the bloke next to me, fighting for brothers in arms, but my medal just reminds me of a lack of appreciation from the army and a lack of help or sympathy with PTSD.'

Harry, tour: Herrick XV, 2011
Object no: L2016-2097

6. Tourniquet

'Some people had a tourniquet on each limb, waiting to get blown up. You only had to carry one, but I carried seven. They weren't for me, they were for the boys. This little device could save our lives. It was given to us to protect us physically, but we didn't have anything to protect our mind.'

7. Monster toy

'My fiancée bought me this as a funny gift, nothing to do with PTSD. I named it after the insurgents that made me ill, and if I was having a tough time this helped. It helped us to laugh about something that was painful. It became a personification of my PTSD, a personality to focus my negative feelings on. He signifies change and recovery for me.'

Figure 6.7: Labels for the "Living with PTSD" case within the *Wounded* exhibition (Photograph by Jenni Hunt)

Each label is credited to the person who created it, acknowledging their input, as well as listing the military tour that they participated in if they chose to share this information. The participants in the project were only a few years on from the experiences which they were discussing and are therefore young men in the film, preventing the distancing effect that the curator was concerned about happening elsewhere. Overall, the participation project was felt to be successful, with the participants choosing to be acknowledged within the gallery.

The Science Museum has learned from this experience, building on it in the redisplay of the Medicine Galleries. McEnroe (2018) explained that they were "working with different groups so they're actually creating some of the content of the galleries, which was a really key part of the project, so that's been short films, audios, but also selecting objects for display." Working with disabled individuals to tell their stories has become an important part of the new Medicine Galleries, with stories from people who have been within the mental health system being presented. This collaboration is part of the Science Museum's ongoing work with participation, which views it as a method of

"building on and extending existing exhibition development practices" (Bunning et al., 2015) in order to create a more inclusive output. The *Wounded* exhibition was not the Science Museum's first foray into participatory projects, but rather part of an ongoing effort by the museum to involve participation across all their work.

Images of individuals with disabilities were also an important part of the Medicine Galleries. This was because evidence from evaluation of previous gallery development said that it was important to have representation that was very visible. Aware of previous representations of disabled bodies and how they have been displayed, as discussed by Snyder and Mitchell (2006), the aim here was to show a "stunning range of portraits and these are going to be nearly life size on gallery, so as you walk through you will literally see people throughout and… so it's something that you'll immediately see" (McEnroe, 2018). The images of disabled bodies are included, but rather than being shown as specimens "they are beautiful portraits in their own right" (ibid.). This again challenges stereotypes and expectations, with images created by a well-known photographer, Siân Davey, who worked with the individuals pictured to show their stories.

Alongside benefitting participants and the audience, such collaborative projects also had a positive impact on the museums that were involved. The ability of people who are experienced in the field of disability rights to highlight nuances of language was mentioned at a couple of the sites. Fox (2018a) spoke of picking up details in language:

> "…just even a simple term like at one point somebody described Down's syndrome as a 'disorder', and I said 'well, we wouldn't use the word disorder when we're talking about Down's syndrome.' Because immediately that's implying that there's sort of a negative connotation, whereas I would use the word 'condition' rather than disorder, so just small things that I would sort of pick up on as a disabled person that maybe other people wouldn't."

This insight was also highlighted by Natasha McEnroe (2018) at the Science Museum, speaking about the access panel for the Medicine Galleries:

> "…when we were testing the gallery text around historic psychiatric hospitals, the access panel said-suggested-felt that we overused the word "patient" too much, that actually if you swap that around for "person" or "people" instead of

patients all the time, then that just subtly reminds you, the reader, that this is in
fact a real person. And it's you know, it's a simple change, but actually quite a
powerful one I think."

This draws on Dodd, Jones and Sandell's (2017) work on trading zones, as the museum
is working with disabled experts and drawing on nuances that they can identify to
improve the end result. This also links to Oliver's (1992) work, showing that both
participant and museum benefit from participatory work.

Across all three sites, projects took place in which disabled individuals played a key
part in the stories that were being told and how information was presented. Having these
stories told in the individual's own words and presented in the way they wished was felt
to increase the depth and detail of the stories told. The voices of disabled people were
used to people galleries, rather than allowing historic sites to be presented as empty and
devoid of life (MacLeod, 2018, p. 15). Instead, the use of disabled voices can empower
those who are heard, and add nuance and meaning for the visitor – as can be seen in the
labels created by the disabled veteran for the *Wounded* exhibition, and the discussion of
challenging words used in the Museum of Liverpool.

Process of Co-Creation

As has been shown, there are a vast number of ways that the case study museums
collaborated with disabled people in order to create their exhibitions. Having examined
the methods used, attention now turns to how such collaboration was carried out, and
the successes and failures that were encountered during this journey.

Running a co-creation project requires time and effort from both sides of the project,
requiring a large commitment from both museum and collaborators. As McEnroe
(2018) explained about the use of co-creation in the development of the Medicine
Galleries:

"We've got a really extensive participation programme with different groups for
example people with mental health issues, people recovering from brain injuries.
So we're working with different groups so they're actually creating some of the
content of the galleries, which was a really key part of the project, so that's been

short films, audios, but also selecting objects for display. So that has been incredibly rewarding, and will be really reflected I hope in the gallery, but equally it's something which is very very time consuming, and takes a lot of investment and logistics and planning. It's not an easy option, but one I think that has been worth doing."

Collaboration brings a range of challenges to museums and to their participants, as they try to balance competing needs and create an effective end result. The goal of creating participatory work that is "genuinely participatory, meaningful and impactful for both museums and participants" (Bunning et al., 2015) is one that many museums strive for, but turning this goal into action can be difficult.

When considering the reasons that museums undertake collaborative work, we can start with the most practical of reasons: funding. I discussed above how the Heritage Lottery Fund (HLF) expects all projects that are gaining its support to ensure that a "wider range of people will be involved in heritage" (Heritage Lottery Fund, n.d.a). This definitely had an impact on some of the decisions around including participation projects for the Science Museum and shaped what could be done by NDACA.

For the Science Museum's Stewart Emmens, the idea of a participation project was initially something that he was quite uncertain about, but included due to precedent from previous work and because

"[The project] was HLF funded, that's something they would like. A box that they would like to have ticked, you know, involving volunteers, collaborating or co-curating with groups to create content, so that was always going to be part of the project, and I was a bit cynical about it at first, I thought 'Oh… you know, it doesn't easily fit the First World War necessarily'." (Emmens, 2018)

Despite initial reluctance to use participation projects, the necessity of their inclusion for funding led to them being a part of the Science Museum's exhibition. As the project continued, and the participation project showed itself to be a success, the initial scepticism lessened, with Emmens (2018) saying one thing he learned from the project was that "participation projects could be very successful", which encouraged him during the larger work towards the Medicine Galleries design. Securing funding might have been the initial reason for including a participation project, but the benefits that were found went beyond the financial.

David Hevey (2018) explained that while HLF funding enabled NDACA to be created, and its support was vital, it also caused difficulties when deciding how to address the story that was being told. This is because they were working on telling a political story.

> "The HLF will ask us 'how are we not funding politics' and our answer is 'you're funding the story of politics', so we got out of some of those problems too. Because, you know, it's quite tricky, you can't actually fund politics in British culture, but you can fund the story of it, so I was able to negotiate that we would do that, and HLF I think needed or wanted, a real breakout of a new form of heritage, is what I think."

Although the movement they presented had been political, by focusing on the history of it, they were able to gain funding that would have been impossible otherwise. Hevey also explained that he felt NDACA's work was a new kind of heritage, one that the HLF wished to support as a contrast to their more traditional funding of churches and railways.

Carrying out participation projects caused a number of difficulties, with questions arising over who could be involved, what was being achieved, and what the aims of the project were. However, these difficulties were outweighed by the successes of the projects.

As discussed above, lack of information about some artists was a problem for NDACA, as was the death of some people they wished to have involved. Trying to work out how to explain and classify artworks was also difficult due to shifts in individuals' identities – however, putting stories in their own words helped to present the information, and enabled the collection to grow. There were also aims to keep the collection growing, in a participatory way:

> "…the notation and exhibition being a sort of two-way process, rather than me deciding "well, your work's important", you have the opportunity of sticking your hand up, coming forward, pushing, being recommended by a friend, and going forward um… We hope to accession a limited amount of new work every year. And that'll be on recommendations from individuals and organisations, disabled-run organisations like Shape and others, what would you like to see, whose work is important." (Cowan, 2019)

NDACA aims to continue to collaborate with the artist community that it was created to celebrate, working with them to grow and to explain their collections. This long-term collaboration with a donor community was not possible at the other sites, due to the differing and temporary nature of their exhibitions.

For Liverpool Museums, the collaboration being undertaken was quite different from previous work they had done, due to being part of the wider History of Place project – something which posed challenges for both sides. As Kingston (2018) explained, it gave them a chance to put access front and centre, and to consider the richness of accessibility and how it could be included. However, working with a range of partners with limited time and budget to try to reach agreement and achieve quality was tricky, especially when some of the museums were seen as fixed in their ways (Fox, 2018b). On the museum side of things, handing over control of text and materials for the exhibit caused some concerns. Difficulties also arose in the practical side of collaboration, such as the use of iPads and trouble recruiting volunteers for some roles.

Overall, however, Jones (2018) felt that the project enabled the space to be transformed, accessibility to be included throughout, and staff and volunteers to be trained. Other collaborative work that the museum has participated in has also provided both challenges and opportunities, with the site working with disabled groups to tell stories that had previously gone unexamined. Jones also highlighted the fact that this project encouraged the Museum of Liverpool to rethink advertising their exhibitions in a more accessible way, and also to reconsider the museum visit for disabled people, examining the route to the museum as well as the museum itself. Collaboration with disabled individuals had brought forwards new concerns, which the museum planned to address in future work, creating benefits for the site and audiences beyond this project. This emphasised the reciprocal nature of the work, showing that they learned from their participation and took that learning forwards.

The Science Museum had to adjust who they were working with as a result of the collaborative process. As Emmens (2018) explained

> "…when we were thinking about the participation project I thought 'well we could have an amputee, we could have someone who has had a facial injury', and then I think after one or two discussions internally we thought 'No. That's

going to be very difficult to do. It doesn't really make sense.' So we thought

we'd pick on a particular group. "

To create a project looking in depth at modern experiences of wounding, it was felt to be important that the participants had a degree of shared experience, so that they would have cohesiveness in the stories they were telling. Using individuals who had a shared experience also enabled the museum to work with the organisation Combat Stress to reach out and to mediate the experience, as well as exploring the topic of PTSD, which was often a "misunderstood wound" (Emmens, 2018), in greater depth.

At the Science Museum, initially the collaborative project was undertaken with a degree of anonymity, with the participants not seen or named. However, as the project continued, the collective choice was made by participants to use their voices, faces, and first names (Emmens, 2020). Emmens explained that this was because "the participants were really happy, they were very proud of it" (Emmens, 2018). Although PTSD can often be stigmatised, those involved in the project were pleased with the end result and wanted their participation acknowledged within the exhibition itself. This change over the course of the project emphasised the successes that took place, and how happy the participants were with the final exhibition.

As discussed above, Oliver (1992) spoke of the importance of reciprocity, empowerment, and mutual benefit for emancipatory research, with all of these being gained via a transformational dialogue. Such results could not be found simply by brief interaction, or indeed by handing over total control of a space to a community group. Instead, a museum and disabled individuals have to commit to working together over time towards jointly-owned outcomes, which has shifted power from being held solely by the museum to being shared between the museum and the participants. Work such as this is beneficial to both participants and the museum, as has been shown using these case studies.

Sharing Authority

Having considered the results and methods of participation, I turn now to the question of how successful these museums have been at sharing their authority. When

considering this, I will use Oliver's (1992) understanding of emancipatory research and try to apply this framework to the work that is done within a museum.

Involving communities in telling their stories within museums has a long tradition, and participation itself is not new. However, questions over taking a more activist role have been hotly debated, with museums preferring differing levels of activism, which can be seen within the case studies themselves. The Liverpool Museums position themselves as deeply involved in social activism, with "Engage and Empower" being one of their key aims within their strategic plan (Liverpool Museums, 2020), and this is reflected throughout their work. The formation of NDACA was driven by disability participation, while for the Science Museum – in this project as in those before – the "end result [is] proscribed and predetermined by the museum" (Bunning et al., 2015). Although for the Science Museum this end goal was fixed, that doesn't stop the participatory work from being meaningful and impactful for both museum and participants.

As discussed above, the participants in the Science Museum increased their involvement during the sustained dialogue that occurred. For individuals who had been affected by PTSD, having their experiences acknowledged and used to teach others provided a degree of benefit. Such benefits were also felt by participants in the Liverpool exhibition, with Fox (2018a) stating that she was proud of "the legacy that happens in the volunteers that have been involved, I mean one guy from Liverpool has gone on and got a job at the museum since being a volunteer with us", and of the networks that were built up. Accentuate is going to work further with museums, with their next major project aiming to increase the number of disabled staff, providing museums with new perspectives.

Participation projects in museums have focused to some degree on power handover (Simon, 2010; Bunning et al., 2015) and on meaningful results, but it seems that here there is a strong overlap between the work of museums and the emphasis on participation and respect within disability studies, with both groups demanding that those involved benefit from their participation. Disability studies focuses also on the idea of doing things with people rather than for them – this can be seen in "Nothing about us without us", but also in the work done by disability arts groups such as Shape Arts, which describes itself as a "disability-led arts organisation which works to

improve access to culture for disabled people by providing opportunities for disabled artists, training cultural institutions to be more open to disabled people, and through running participatory arts and development programmes" (Shape Arts, 2020). By placing the emphasis on the cultural institution becoming accessible, Shape is able to pursue the social model and help institutions do the same.

Museums can find it hard to share power, trapped within hierarchies and silos and unwilling to change (Smith and Fouseki, 2016, p. 478). Work done by the People's History Museum in Manchester examined the importance of making use of interpretation in a relevant way, including a range of themes and active participation to increase visitors and build relationships, changing how participation was handled within the organisation and leading to an engagement officer being a part of the core team (O'Donnell, 2016, p. 406). If we are to see museums doing social justice work, they will need to be willing to challenge traditional hierarchies and to ensure everyone is clear about what the projects undertaken are being used for. This is why the Museum of Wales has trained its trustees in participation (Smith and Fouseki, 2016, p. 484), something which they found worked successfully.

As Avram and Burcea's (2016) work showed, initial attempts at interaction, especially with marginalised communities, can be viewed as insincere, with people arriving full of anger and frustration (p. 539). Only by proving themselves as willing to listen and to work with a group for a long time was the museum involved able to gain the trust of participants and create results which are both enjoyable for visitors and empowering for participants (ibid., p. 541). This ongoing commitment, as well as opening up to critiques, allows museums to make meaningful connections with the communities they serve, and helps the museum to become "an active participant in society" (ibid., p. 558), encouraging communities to use the space for discourse and engagement.

Simply concentrating on handing over power, however, can be seen as a polarising red herring (Govier, 2010, p. 4). Rather than seeing power handover as an abandonment of responsibility by museums, museums must "have to have the intellectual courage to select what goes up on your walls. Then you have the responsibility to stand by it" (Dubin, 1999, p. 239). The museum has to be willing to support what it displays, and to work with different groups, including those that are marginalised. Working with groups

isn't a problem for museums alone – it is a challenge seen within businesses and other arts organisations, and so museums can search widely when looking for advice and to ensure relevance. Collaboration is not easy, with various groups having firm agendas (Govier, 2010, p. 16). However, the results of collaboration are valuable and worthy of encouragement, with non-professionals having a lot to bring to the creative process and being able to shape and change the end result (ibid., p. 27). Museums of all kinds can take part in participation projects, which can benefit the site itself and its audiences, along with the participants themselves, as has been shown here.

Participation allows for visitors to have a different kind of engagement, helping to tell different stories (Sandell, McSweeny and Kavanagh, 2016, p. 581). These academics argue that the best results come when participation is not seen as an add-on, but as a key part of what is being focused on, and when museums are willing to express certain views and ensure visibility (ibid., p. 587). This focus on participation was seen within all three case studies to a greater or lesser extent, with both the Museum of Liverpool and the Science Museum taking what was learnt and using it for future projects to continue to improve what is offered to the audience. When telling stories of disability, where representation and political involvement play such a key part, participation projects have a major role, as they allow people to talk directly rather than being spoken for (Graham, 2016, p. 260). This is of benefit by allowing a range of voices to be heard, alongside challenging previous dehumanisation of disabled individuals.

Participation projects aren't being done to replace the museum narrative, and still require the museum's authority behind them to be respected. Instead of replacing the narrative, "they disrupt and complicate it, they critique it and they enrich it" (Sandell, McSweeny and Kavanagh, 2016, p. 591), encouraging the audience to consider topics and questions in new ways. Exhibitions which involve a sharing of museum authority can not only benefit participants and museums, but can also allow audiences to gain new insights and greater understandings. The holistic approach (Bunning et al., 2015) needed is more than just handing over authority, and instead requires collaboration and mutual consideration to be of maximum benefit to all who are involved. Whatever form a collaboration project takes, ensuring mutual respect and reflection leads to the best possible outcomes.

Conclusion

All three case studies here have made use of participation projects, and other methods of working with disabled individuals, to get disabled voices into the galleries telling stories around disability. They have found a variety of ways to work with disabled people to produce the final displays. The precise reasoning for these projects, and the methods that they chose to use, differs. However, there appears to be a general acceptance about the importance of collaboration and inclusion, along with a realisation that such work is seen as crucial by funders. Museums, like many different areas of society, are trying to work with underrepresented groups to ensure empowerment and emancipation, and to enable a plurality of voices to be heard.

The purpose behind this collaboration links to the ideas driving these exhibitions more generally: considering underserved and undervalued audiences, allowing for representation, and taking part in social justice. This relates to wider considerations of disability, empowerment, emancipation, and human rights, and the important role that museums can play in changing attitudes and educating the public.

The next chapter examines the purposes behind these exhibitions as a whole, considering the reasons that their creators give for why they were carried out and the messages they hoped to share with the audiences. The idea of representation and justice which will emerge links with the motivations that we have seen within this chapter, which has focused on the participatory elements of the projects. This thread is shown to underpin the thesis. By taking a step back and linking this to the motivation behind each of the case studies as a whole, a deeper understanding of purpose can be gained, and links between the collaborative projects and the wider exhibitions can be drawn out.

Chapter Seven – Purpose of Presentation

Introduction

The research within this thesis has shown that museums are increasingly working to tell stories around disability which have previously been hidden, and that they aim to do so in a variety of different ways, often with the support of those portrayed. The case studies that have been examined, and the various other examples touched upon, have all addressed disability, usually relying upon the social model. The last chapter has revealed how very often work around the display of disability has involved collaboration with disabled individuals to tell personal stories. Such work requires large commitments of time and energy from all of those involved, with little guarantee of success. The potential challenges that such collaborations can involve raise the question of why museums are choosing to approach disability in this way, and past difficulties around the display of disability can lead us to ask why museums are choosing to address such a topic at all, especially when it was not previously represented.

Disability has been viewed as a difficult topic to display, as was made clear within Chapter Three, which examined the representation of disability within different media. *Buried in the Footnotes*, a one-year research project by Dodd, Sandell, Delin and Gay (2004) aimed to explore the representation of disabled people in museum and gallery collections. At this time, it was discovered that while museums held a large amount of relevant material, they often did not display it, due to uncertainty about how to do so and fear of causing unintended pain. This thesis' research, carried out fifteen years later, found several examples that were tackling disability head-on and addressing challenging issues. This suggests that something has changed across the intervening time, in terms of the attitude of museums and their staff towards disabled people. Within this chapter, I will try to explore the changes that have taken place in the attitudes of museum staff towards disability.

This chapter examines the role of the museum and of the stories that are being told, focusing on what it is that museums aim to achieve by holding such exhibitions and why the exhibitions are taking place now. In doing so, the chapter investigates the

motivations and intentions behind various displays, linking these to the issues around disability and human rights that were discussed within Chapter Two. It also investigates the idea of museums acting with a social purpose, which was explored earlier within the thesis, and considers the messages that museums are aiming to convey to their visitors when they carry out such exhibitions. From discussion with staff members, it considers the response of the audience to what they have seen, along with the attitudes of staff to the completed exhibition. This discussion will then lead to the next chapter, which evaluates the extent of what has been discovered and examines the key findings as to how disability is being viewed and shown within collections, raising issues of integration, segregation and how representation of disability will continue in the future.

Purpose of the Exhibitions

Earlier in my thesis, I examined the links between museums, disability, and human rights, emphasising the work that could be done by museums to support human rights and especially the rights of individuals with disabilities. I highlighted examples from the literature in which museums had worked to support the agency and independence of disabled people.

I also considered previous attitudes towards the display of disability, including earlier hesitance, and examining how varying types of work have been done to move disabled people "from the margins of history" (Telfer, Heaton and Anderson, 2011, p. 16). At first, such work was approached with caution by museums. In the intervening years, attitudes towards the suitability of disability as a topic for display seem to have shifted, and in this chapter I hope to examine the attitudes of staff involved in the case study exhibitions to see what their motivations were for approaching disability as a topic – if it is viewed simply as part of their work to widen the stories covered or if there are other goals driving them.

In Chapter Two I highlighted Article 30 of the UN's Convention on the Rights of Persons with Disabilities, which sets out the rights of disabled people to participate on an equal basis in culture, recreation, leisure and sport, and states that disabled people "shall be entitled, on an equal basis with others, to recognition and support of their

specific cultural and linguistic identity", putting a legal obligation on signatories such as the United Kingdom to ensure that this is met (UN Enable, 2007). I will analyse this in further detail below.

My attention now shifts to the work carried out within the case study sites, with the goal of exploring the motivation behind such presentations of disability. To do this, I will draw upon the interviews held with museum staff, picking out various themes which were repeatedly raised within discussions and exploring how these relate to the ideas discussed so far, particularly considering what has been examined already in this thesis in terms of human rights.

I have selected three key themes that were mentioned in terms of the motivation for including disability representation within museum displays: the idea of a lack of representation and understanding, the concept of representation as part of the museum's programme, and the emphasis on sharing stories and creating partnerships. Alongside these stated purposes, I also explore the goals that the museums have for their audiences when interacting with their exhibitions, examining in particular the key message that they wish for their visitors to leave with. By considering both motivation and goals, I believe an understanding of the intended purpose of the exhibitions can be achieved.

Missing representation

As has been discussed, museums are increasingly aware of who they are representing – and who they are failing to represent – within their exhibition programmes. These hidden histories are increasingly being uncovered and highlighted within museums and historic sites. For example the British Museum's recent trail *Desire, love, identity* (British Museum, 2018) aimed to pick out objects linked to LGBTQ histories within the collection, whilst the National Trust's *Colonial Countryside* project (2018) aimed to work with children and authors to explore the colonial legacies of historic houses. Within this wider move by museums towards the representation of hidden histories and sharing stories that had previously been overlooked, it is perhaps not surprising that stories around disability would also receive increasing attention in a range of different collections.

The idea of filling in these historical gaps, examining where previously disability had been ignored by museums and historical sites, was raised in a number of the interviews carried out within this research. The implication of this is that disability is being considered for exhibitions because it was not shown before, and as museums aim to become more representative, they are targeting what they feel are holes within their collections.

Whilst Fox (2018a) highlighted a number of previous small-scale displays, she also stated that there were no larger-scale projects prior to History of Place. History of Place aimed to explore the architectural impact disability had on the built landscape, tackling eight hundred years of disability history across eight different locations. She felt that "it was really needed for us to develop a social history programme that told you about the lives of disabled people all over that whole time period" in order to draw out connections between different locations. She explained she approached museums saying "we're not doing enough to tell the stories of disabled people in our collections" (ibid.), and their agreement with this caused them to become involved. This shows a willingness to tell these stories, but also a previous caution in approaching them, which I will consider in more detail below.

For the Science Museum, war and its impact were viewed as an underexplored topic (Emmens, 2018). On the centenary of the First World War, telling these stories and looking at the social impact of war was felt to be a chance for the museum to reflect social history, whilst also tying in with nationwide events to commemorate the global impact of the First World War. Similarly, for the NDACA project the work served as an opportunity "to tell stories that have never been told before, and make audiences aware of them" (Cowan, 2019). This was felt to be a gap that museums had previously ignored, and which could here be considered in far more depth. The NDACA project was set up to fill a gap within the collections of other museums and archives.

For many of my interviewees, this was not their first exploration of hidden histories. These were often a topic that they felt passionately about, whether they were focused mainly on the representation of disability or involved in wider examinations of hidden histories. Kingston (2018) spoke about her work with the *Rainbow Jews* (2013) project, celebrating the LGBT history of Jewish communities within the UK, whilst David

Hevey (2018) had longstanding engagement involving making "radical culture but for millions" around the Disability Rights Movement that he had been a part of for several decades. Hevey spoke of his respect for the disability rights story, born out of his personal experience and the exclusion that he had faced. Such personal commitment helped to drive these individuals to push for inclusion that might otherwise have been overlooked – they had decided that representing different groups was important and so sought out opportunities to do this within their work, with their own involvement helping to further increase representation.

This personal commitment was supported by a willingness to fund these projects from the museums and the Heritage Lottery Fund (HLF). The Science Museum decided that how medicine was represented needed to be improved, highlighting it within their rolling master plan, as previous exhibits were viewed as dated (McEnroe, 2018) and in need of work to make them more relevant and engaging to the audience. This led to the development of the Medicine Galleries, but also helped shape the decisions around holding the *Wounded* exhibition as a part of the Museum's First World War commemorations. Both of these exhibitions relied on funding from a number of sources, including the HLF. For the *Wounded* project, the application went through several iterations (Emmens, 2018), with the amount of money requested varying greatly; however, eventually funding was granted for a smaller-scale project. The museum might not have received the amount that they had hoped for, but the fact the HLF was willing to invest in this project at all again reiterates that this is a topic felt to be appropriate for public funding.

Being considered suitable for investment was also true of NDACA, which was campaigned for by Tony Heaton and others for decades (Hevey, 2018) and eventually received funding in 2012 from the Heritage Lottery Fund. Although the overall concept had not changed, what was seen as appropriate for funding had shifted over time, with the funding here linked to the impact of the Cultural Olympiad, which ran alongside the 2012 Olympics and Paralympics, and which featured the work of disabled artists heavily (British Council, undated). For Hevey, choosing to fund NDACA was an attempt by the HLF to avoid becoming "obsolete by being strangled by basically middle class, bourgeois, boring, values of nothingness" (2018). For him, the story of disability linked to sharing stories of dissent, and in doing so finding a way to interest and engage

the public - as he explained, rather than saying "'yippee, lower middle class values preserved', they all think 'come on let's do something interesting'" (2018). A desire to share these stories led to the funding for the NDACA project, as well as a number of other disability-focused stories. The project's disability focus was also enhanced by the decision to tell stories digitally, and to pioneer digital heritage, in order to enable a wider sharing of this story.

Stories around disability have been overlooked in the past but they are now being shared, and museums are increasingly finding that funding is available for them to get these histories out into the public domain. Such support makes it easier for museums to engage in the human rights work that was discussed above, and which is seen as increasingly important to their purpose by a number of significant figures. Indeed, NDACA's work on cultural representation can be linked with Article 30 of the UN's Convention on the Rights of Persons with Disabilities, which sets out the right of disabled people to have "recognition and support of their specific cultural and linguistic identity" (UN Enable, 2007). Representing disability culture is not only an ethical consideration, but also a task that the UK – as a signatory of the convention – is legally obliged to undertake, meaning projects such as NDACA are more likely to gain support.

Driven by the urge to be socially relevant and to engage with a range of audiences, museums are increasingly including disabled individuals. However, there is no certainty yet that such temporary thinking will lead to lasting change. Despite the success of History of Place, Fox (2018a) expressed concern as to whether disability history would be included in future work:

> "I just don't want it to be another one of those great projects that lasts for like three years and then it suddenly all stops again. Because I think there's still so much that needs to be done."

One possible solution to this would be to ensure that disability is considered within a museum's programming more generally, rather than serving as a topic for specific temporary exhibits as part of an attempt to represent diverse groups alongside the main programme. I will explore this idea far more within Chapter Eight.

Recognition of a previous lack of representation around disability is one reason for the increased inclusion of such ideas within current museum exhibitions. However, as will

be shown, it is far from the only reason behind this shift that has been seen over the past couple of decades.

Part of the Core Programme

In direct contrast to the idea of disability being something missing from the collections, at times staff felt that disability was focused upon in these exhibitions because it was viewed as being at the core of the work the site was carrying out. This most obviously applies to NDACA, whose entire purpose is to enable disability representation. However it was also viewed as key by the Museum of Liverpool, which sets out in its strategic plan (Liverpool Museums, 2018a) its goals of being representative, engaging, empowering, and of having people at the heart of the collection. With the strategic plan stating that "colleagues, audiences and displays need to be representative of the communities we are here to serve", the museum aims to reflect the people and communities located around it, which will include disabled individuals.

In keeping with this, the Museum of Liverpool had previously created a number of smaller displays using objects related to disability, alongside blogs for disability history month. Kay Jones, curator at the museum, explained

> "When we developed the concept of the museum we wanted to make sure there was content relating to different kinds of communities represented and embedded across the whole museum, so it wasn't just a temporary exhibition that would change and there'd be no representation…" (2018)

This shows that rather than such communities being considered as an afterthought, they were central to the programme from its very creation across different galleries, so that "disabled people's stories are embedded within wider histories, and not just kind of ghettoised" (ibid.). Often, stories around disability can appear as an afterthought. However, that was not the case here, and this is something that will be explored in more depth within Chapter Eight.

The curator went on to set out how disability has been included throughout the museum since its opening in 2011.

> "We've got for example a trail across the museum, we have various ones, but this is called 'Trailblazer', so you might see on the labels in the case a trail

symbol and we made sure that there were kind of pioneers in relation to people within the local disabled community featured within that – people who set up the deaf school for example, and also a display about Edward Rushton, who was a blind pioneer, he was one of the people who helped set up the school for the blind but he also campaigned against slavery as well. And that was one of our 'In Focus' community changing displays, so we've tried to embed content as much as we can – we've done big temporary exhibitions, like *The Blind School*, the Wicked Fish exhibition but also smaller 'In Focus' community group displays, but also just objects embedded within displays across the museum as well." (ibid.)

In this way, the Museum of Liverpool has aimed to show stories around disability at all levels of its exhibitions, tied in to "big themes like sport, music" (ibid.) and the like rather than being isolated or closed off. This links to its rights-based programming and the museum's goal of representation.

As the museum opened relatively recently, such social justice concerns were central from the very beginning and could be built in from the initial discussions onwards. For older sites, it may be harder to include previously ignored stories at a foundational level. However, they can still be represented in numerous ways, drawing on what already exists within the collection and emphasising the links to these stories, including at times accessioning new items which help them to tell the stories they wish to deliver to the public.

For example, within the Science Museum, representation of disability has become viewed as a part of the organised programming, building on previous work and serving as one of the important topics that the site aimed to cover. The exhibit that became *Wounded* had its foundations in an exhibition idea from ten years before, suggested by Emmens (2018), in which he wanted to consider contemporary responses to battlefield injury and the path that the wounded soldier took from the moment of injury to recovery. This shows the role his own personal interest played in the project. However, this proposal was not pursued further at the time, and was only revisited when it came to the centenary of the First World War, at which point the focus was shifted from contemporary treatments to historical ones, as Emmens explained:

"When the museum… very publicly said 'Yes, of course we will be commemorating the centenary of the First World War', without any plans in place, they… got this out, sent it to me and said 'Can we do something similar for World War One?', so that's where that started." (2018)

With the centenary of the First World War being publicly commemorated, the museum felt that there was a need to mark this anniversary, and the topics covered by *Wounded* enabled them to do this whilst making use of their existing collections.

However, early on there was a disagreement about what the actual purpose of the exhibition would be. As discussed above, a senior member of staff at the museum spoke of it as celebrating the triumphs of medicine; yet the staff involved in the exhibition disagreed with this. Emmens highlighted the complexity of the story that they were addressing. Whilst the exhibition offered the Science Museum the opportunity to examine the story of medical development within the First World War, it didn't tell a simple story of scientific victory. Instead, effort was made to consider the failures as well as the successes, to show the problems that emerged and to consider mistakes made. For the curator at least, the point of the exhibition wasn't to show the victory of medicine, but to instead try to present the nuance and challenges of the situation that occurred during the First World War, recognising the fact that many men were left with "unbelievably horrible injuries, to which medicine then didn't have an answer to a lot of them and still doesn't now" (ibid.). His research presented him with things that he found difficult, injuries that he wished that he could unsee, and he wanted this acknowledged within the exhibit in a way that humanised rather than othered those involved and was appropriate for the audience.

Rather than focusing solely on medical victory, Emmens also wanted to explore the limits of medicine. This is something reflected within the Science Museum's Medicine Galleries, with one of them, *Faith, Hope and Fear*, examining cultural and religious items linking to hopes and fears about health (Science Museum, 2020a). Much like this gallery, the presence of lucky charms at the entrance of the *Wounded* exhibition (Figure 7.1) shows an awareness of the limits of science and a consideration of how scientific knowledge intersects with other beliefs. Placing the charms so prominently suggests an exploration of the nature of science, including the limits, whilst also showing the role of luck in injury and survival.

"Men weren't very protected, you know, didn't even have helmets until a year into the war, they carried lucky charms, but I also wanted to get the idea… that… you know, a lot of it, whether you're hit in the first place or if you get reached in time, or if you get treated by the right kind of doctor who knows what he's doing, or who is using a technique that works… a lot of it is down to luck." (Emmens, 2018)

The charms placed early on in *Wounded* symbolise this, showing the superstition that many of those caught up in the conflict clung to and tying to broader considerations of belief being pursued by the Science Museum. They were also a chance to show individuality – there were no names attached to the charms, but the variety of objects on display helped individualise the soldiers who were being discussed within the exhibition, allowing small amounts of personality to shine through by acknowledging that such charms were "given by family and loved ones, bought commercially or chosen for personal significance" (Science Museum, n.d.).

Figure 7.1: Lucky charms featured in the *Wounded* exhibition (Photograph by Jenni Hunt)

The exhibition's focus on the violence of war and the impact it had on the lives of those affected was not always well received:

"…one of the first presentations we did, probably back in 2011, and we got some visuals, and somebody at the end said 'Nobody is going to come to this, you've just shown me all the horrible things that can happen to someone on the battlefield' and so there was a question about what you can show, because I've… you look through a book this thick of First World War facial injuries and it's just… you know, it's just unbelievable. But then you want to talk about facial injuries, what can you show. So there's a question of what level of injury and… you know, some people involved in the project just said well we shouldn't really show anything, and then there were one or two who were just like 'let's really show some of the extreme stuff' and then… we ended up with we're not going to show huge amounts but we are going to show some, so there was… the Tonks pastels, with facial injury stuff, were… I mean they're a fantastic thing to be able to borrow, but they're quite… they sort of suggest the horror of this, but because they're um… they're a sort of pastel drawing… you know, they're not quite as difficult as they would be if you just showed photographs. But um, then we did have a couple of battles – there was two pictures of someone with mustard burns… mustard gas burns, sort of the whole body almost you can see, and then there was a close up of someone with… an anaesthetic up their nose, because their mouth was basically gone… um… and that had to be cropped. The original photo, the project manager said either we crop it in or it goes. So we cropped it in in the end, although we did in the last sort of… draft, we pulled back a little bit, and got a bit more in. So there is… there was, yeah, that presentation of… it's difficult to do an exhibition about wounding, and to talk about how terrible it is, and how difficult it is to deal with, and the sort of particularly unusual types of wound you're getting without showing some of that." (Emmens, 2018)

In this quotation, Emmens touches on some of the questions that surround the purpose of museums and what it is suitable for museums to contain. The stories that were being told by this exhibition were those that related to life-changing injuries, and yet throughout attention had to be paid to the attitude of visitors to ensure that the information provided interest rather than repulsing viewers. This ties to Sandell's (2007) work on naming, in which he evaluates how some displays might alienate audiences and encourage othering of those viewed rather than aiding understanding.

People who were injured in the war are often regarded as heroes, and this often precludes them from being considered as disabled due to the stereotypes around disability. Indeed, on the Royal Museums Greenwich (2018b) webpage about Nelson, no mention is made of his disability. By framing those who were wounded in the conflict as disabled, and affected for the remainder of their lives, the Science Museum was challenging people's preconceptions and understandings of this war.

It is worth considering the fact that the First World War was not a new topic for the museums' audiences, and it was not intended to be – instead the goal was to bring out new stories from a known setting; to make something familiar of interest; and to draw links between injuries of the past and conflicts of the present, as was seen towards the end of the exhibition when effort was made to move the discussion to more recent conflict and injury.

Similarly, for NDACA the goal was to build on already familiar stories, "widening the audience, rather than creating one from scratch" (Cowan, 2019). While the story of disability art had not previously been told in the way that NDACA aimed to do, the figures shown are not entirely unknown to the audience, with many being embedded within popular cultural awareness. This familiarity is intentional, as Cowan explained: "everybody recognises… at least one of the figures that we've got on the archive, even if it's just Liz Carr because she's that lady off the telly in the crime drama." (ibid) He aimed to draw out those connections, in order to help audiences access what they were being presented with.

For Cowan (2019), disability arts was a topic that would be recognisable to a lot of people within the audience.

> "I realised when I started working on the project … how much of the Disability Arts Movement was already part of my life. How much I'd seen Matt Fraser, popping up on television, and presenting, and you know, confronting me throughout my teenage years and early twenties. I'd been to see Graeae a number of times independently, when I lived in London in the 90s. I'd, you know, we all watched the Paralympic opening ceremony and went 'Wow', because it was… it was… and how that seeps through, how disability arts was… sort of a part of my career, as consumption of British culture."

Such familiarity helps the audience to engage with the stories that are being told.

The fact that these projects are getting funded suggests that there is an interest in them, and a desire to invest, which is supported by the work that is taking place elsewhere in the sector and a shifting understanding of the role of the museum. Whether this conversation is new to the museum or part of their existing goals may vary, but the conversation itself is increasingly important and as such increasingly likely to attract funding and to therefore find space within museum galleries. All three case study sites, and many others, are choosing to openly engage with stories of disability, which links to wider considerations around underrepresented groups and the rights of disabled people.

Sharing Disabled Stories

Alongside ensuring representation for overlooked groups, or simply including disability within wider inclusive programming, some of the individuals involved in my research spoke of the possibility of using the representation of disability to share interesting and compelling stories. These are stories that they want their audiences to hear, because they feel that these stories would be of interest and value to their audiences and are worth sharing within their sites – not because of issues of fairness, but instead because they believe that these are histories that their visitors would like to hear about and have the chance to interact with. Cowan (2019) states that "people are naturally curious about other people's lives", and the work done at these sites aims to encourage and respond to that natural curiosity, and in doing so tell an interesting story that the audience is able to engage with.

This point was also raised by McEnroe (2018) from the Science Museum, who explained that her key goal for the Medicine Galleries was "to make it relate to real people and to tell real stories". To her, stories about medicine are something that all people can relate to as medicine forms a part of all our lives, regardless of culture or experience. She tried to connect the stories that are told within the exhibition to a wide range of people who are visibly shown in the gallery, enabling the variety of humanity to be explored and "challenging people's assumptions about human form" (ibid.). This variation is emphasised both in the stories told, and by the inclusion of images of a range of bodies within the gallery, as has been discussed before. By considering the

variety of stories that exist within humanity, negative stereotypes and assumptions can be tackled and more positive considerations shown, as seen in my previous discussion around the collaborative projects which were undertaken.

The idea of using exhibitions about disability to share stories was also discussed by Hevey (2018) of NDACA, who explained his own respect for the history he was telling and the importance of sharing it to challenge stereotypes.

> "I also had respect for the story, because I was in the story. You know, respect for what had built up. It's quite incredible you see, the whole thing about disability rights is it is incredible. It's counterintuitive, the people you think would be, I suppose passive and grateful, being the most radical and angry. That's what's so interesting."

To Hevey, the Disability Arts Movement is a sign of people going against stereotypes, challenging what is expected of them and proving themselves capable. This links to Hall's (1997) work considering cultural representations, and wider considerations of how different groups have taken control of their own stories, as can be seen in the Harlem Renaissance movement of the 1920s and 1930s, which aimed to reclaim black culture and tell black stories. Telling the story of the Disability Arts Movements gives disabled people a chance to be seen differently. This change of view applies both to disabled individuals and also non-disabled individuals who interact with these stories.

Hevey emphasised the possibility of considering the outsider and telling a story that had been hidden before.

> "It's about being seen… and all my work really is about the outsider, who sees themselves as much more, as richer and more textual than they are positioned, so the other is as complex as the mainstream, and the oppressed working class, women, black people, statelessness, disabled, you name it, are as complex and interesting, and I always say have more agency [than those considered insiders]." (2018)

The stories being told here are different from those traditionally shown in museums, and show a move towards museums being "vital, valued and socially impactful spaces for culture" (MacLeod, 2018, p. 14), and aiming to provide audiences with a new perspective. The story being shared is there to challenge assumptions and reveal truths that the audience might previously have been unaware of. The story of disability rights

highlights how disabled people and allies worked together to change the law, and in doing so goes against some of the stereotypes disabled people have been faced with which cast them as weak or powerless (Church, 2006; Nario-Redmond, 2010).

Hevey (2018) considered the anger that drove the Disability Arts Movement, which was something that he wanted to convey.

> "I mean, when we all were starting, we were all skint working class - I mean the interesting thing about Disability Arts Movement is a lot of the… the vast majority were working-class disabled people, they had nothing to lose. I mean I had nothing to lose. I had… I had no way into the system of power, I didn't understand privilege and power at all, and we just threw bricks at what we thought was wrong. So… cultural bricks. Metaphorical, Foucaultian post-structuralist bricks, but bricks nonetheless."

The story he was aiming to tell was one of rebellion, fighting back against concepts of disabled people as passive and reliant. Challenging these stereotypes by disproving them with memorable stories aims to get visitors to rethink their prior understandings of disabled lives.

Within *Wounded*, one of the goals for the curator was to explore the kind of stories about war that were often ignored. Emmens (2018) explained

> "I'm quite interested in military history… it was a time when there was an awful lot of news reports coming out of Afghanistan, you know, 'one person killed, ten wounded' and those people killed, to be named, tended to come home with honours… I don't know if you remember the people lining the streets as these people, these bodies are brought… and I sort of thought what happens to the… what's the story of these wounded people? Have they lost a finger or have they lost both legs and got brain damage… what's going to happen to them? And what happened to them… you know how are they not dead and how… so if they were seriously injured, you know what happened, and what happens in the longer term?"

These stories of the journey injured soldiers take from being non-disabled to disabled were not often seen in the media. But it was these journeys Emmens wished to explore, considering both the changes that occurred to the affected soldiers' lives and the support which they received.

Such stories are often absent from museums. The National Army Museum, which reopened in 2017, does feature a small amount of information about recovery, when talking about society, however it only makes up a tiny fraction of the overall story. Meanwhile, the Imperial War Museum's *First World War Galleries* barely mention injury or recovery, focusing as Carden-Coyne (2010) explained on the stories of death and survival, rather than acknowledging the impact of wounding and disablement. *Wounded* provided an opportunity for these narratives to be the focus of the display.

Stories about recovery also gave Emmens an opportunity to go beyond the fixed dates of a conflict, instead considering lifelong rehabilitation. For Emmens, this exhibition was an opportunity to combine "cutting-edge trauma medicine" with "an underlying human story" (2018). While the end result focused on historical rather than recent conflict, there remained the consideration of the lifelong impact and change to a life path that wounding caused. In doing so, he addressed both medical and social challenges.

> "It's very much a medical story going from that saving a life in those seconds and minutes to when someone's back home, out of danger, but they've got no legs – what then continues to happen in terms of rehabilitation, what happens, how do they return to civilian life? So I sort of thought that on one hand it was… a sciencey exhibition because… you would have that very cutting-edge trauma medicine and you know, those technologies, but there would be an underlying human story, and I'm not… I'm not sort of naïve that people weren't aware that um… that people were being injured out in wars like you know in Afghanistan, but I sort of thought it was sort of an opportunity to get some of that across. That these people, who may be briefly mentioned in the headline, have got to deal with this for the rest of their lives." (ibid.)

Emmens emphasised that he didn't want to be seen as telling a political story or taking a moral standpoint about war, but instead wanted to focus on the social impact that medicine had on the lives of those who were injured, who are often left out of our understanding of conflicts.

This tied in with Carden-Coyne's (2010) work, which acknowledged that while "wounding and physical and psychological disablement remain major legacies" (p. 64)

of conflict, they are often legacies which are absent from war museums. Similarly to the return of bodies to people lining the streets, she finds that "the dead and the dying are valorized while the disabled are largely ignored" (p. 66), with the disability and pain left after the conflict potentially too difficult for museums to wish to tackle. The Science Museum aimed to engage with these issues. Emmens was inspired to do this from stories he had heard about the interwar period, with disabled veterans begging on the streets, and the connection between those men and more recent wounded individuals who seemed to have been forgotten – wounded men and women "who had to then cope and deal with what had happened to them" (Emmens, 2018). It was felt by Emmens that this story was often missed, due to a tendency to focus on the number of fatalities and the simpler narrative that provided. By sharing these stories, visitors would learn to see a new side to a familiar conflict.

The idea of war as an event which affected the remainder of an individual's life was of particular significance to Emmens, as he linked it to his own memories from his childhood, speaking of family stories that seemed to be passed down from one generation before. This desire to show the war's impact across a life course was reflected by the objects he chose to include, such as "a fantastic artificial limb which has been repaired and repaired, and I… wanted that to suggest you know, somebody wore this for years and years and years" (ibid.). The use of a repaired prosthetic leg (Figure 7.2) shows that the effects of the war lingered for many years, shaping the life stories of those who had been caught up in it.

Figure 7.2: Repaired prosthetic leg within the *Wounded* exhibition (Photograph by Jenni Hunt)

The presentation of this particular prosthetic shows a more human element: the idea someone would choose to repair their limb themselves rather than get it replaced. Although there is no explanation given for why this might have happened, the object itself serves as a motivation for the audience to ask questions and to come to understand what it is they are being shown. The story implied by the leg is interesting, and by highlighting this artifact the museum invites viewers to contemplate the life that exists behind it and to wonder about the individual who made use of it. It also suggests a highly personalised story, distinct from some of the other artificial limbs – it may have been mass-produced, but the repairs it shows indicate that it was used by a particular person, and for a long time.

My third case study also made use of stories, encouraging people to reconsider familiar ideas in new ways. Kingston (2018) spoke of her passion for buildings, and of exploring how buildings are adapted to disability. She felt that presenting the exhibition at the Museum of Liverpool gave a chance for a greater understanding of the history of the

site, showing visitors how disabled individuals had shaped the city that they inhabited over time, and in doing so offered a new perspective of the story of the city where they lived. In this way, the exhibition encouraged the visitor to look at their surroundings in a different way.

This link to an individual curator's own story was also shown by Hevey (2018), who was involved in the Disability Arts Movement. He felt that his involvement was therefore personal, and he emphasised his desire to make sure that the work done by NDACA was something that those involved in the Disability Arts Movement would recognise. He wanted to ensure it was accessible to those unfamiliar with the movement, but also involved the stakeholders – to both bring stories to new audiences, and to make sure that those whose stories were being told would feel included in what was being shown.

In all of these cases, the goal of the exhibition was to share stories and ideas with the audience using new methods, and to help them look at objects and histories in ways that they had not done previously. For the sites discussed, these stories were felt to be compelling, something that the exhibition creators wanted to show to their audience - not just to fill a gap in the collection, but because these stories were interesting in their own right. These stories also set out to challenge those that the audience may have been expecting to find within the exhibits around disability, emphasising agency and the voices of disabled individuals.

Collaboration and Accessibility

Alongside the chance to share new stories, presenting exhibitions focused around disability provided sites with the opportunity of working in new ways, collaborating with different groups and drawing on those with lived experiences of disability, all of which was discussed at greater depth within the prior chapter.

For the Museum of Liverpool, involvement in this project provided the chance to consult with Accentuate in their History of Place project. Accentuate already had a lot of experience in supporting and promoting disabled individuals in the cultural sector (Accentuate, 2020). The collaboration provided an opportunity to work with disabled

individuals, draw on their expertise on sharing information accessibly, and to tell the story of the School for the Blind in a "big way" (Jones, 2018), unlike previous smaller-scale community exhibitions. Collaboration is a key goal for the Museum of Liverpool and so this project provided that opportunity as well as the representation discussed above, enabling collaboration with other sites and with Accentuate and giving the chance for increased knowledge. The importance of collaboration and lived experience was also stressed by Hevey (2018) within the NDACA site, who explained that he had experience of "delivering radical content without frightening the horses," and that this experience helped him to get funding and to approach the topic with confidence.

The Blind School exhibition was a potential learning opportunity for the Museum of Liverpool, with Jones (2018) saying the chance for accessibility "was going to be really important for us and will hopefully help us improve and be more reflective and responsive". This shows how they hope to build on what they have learned from collaboration, in order to ensure that future exhibitions are more accessible for disabled individuals. This shows that representing disability is seen as a core part of their work, as was discussed above. Rather than considering disability to have been covered by this exhibit, work is ongoing to embed such representation throughout their site, learning from what was discovered during this project and taking this forwards.

For Esther Fox (2018a), the Head of the Accentuate Programme which ran History of Place, her own lived experience was key to why she felt she should be involved with the project:

> "…because I just felt it was really important that disabled people's voices were heard in the narrative as well. So I kind of helped along with the curators… And that was quite an interesting process, because there was quite a lot about language that I picked up on, that I think if I hadn't had my politicised head if you like of being a disabled person they probably wouldn't have always realised that the language wasn't quite right, or the tone wasn't quite right. Just even a simple term like at one point somebody described Down's syndrome as a 'disorder', and I said 'well, we wouldn't use the word disorder when we're talking about Down's syndrome.' Because immediately that's implying that there's sort of a negative connotation, whereas I would use the word 'condition' rather than disorder."

Fox felt that her own experiences of disability meant that she had something to bring to the collaboration, an idea that was echoed in the words of the other people who were involved in the project, who stressed what they were able to learn from it. Due to being deeply involved in issues about disability rights and the debates within the disabled community, Fox was able to ensure that the exhibition didn't alienate disabled individuals and to identify relevant stories working alongside other disabled people who were consulted at each site.

The opportunities Fox's involvement provided were something that Accentuate wished to build on in the future by encouraging museums to hire disabled staff (Accentuate, 2021). As well as within museum collections, disabled people are also underrepresented within museum staff. Fox spoke about the fact that disabled and Deaf curators "have a lot to offer, because they would bring new insight, they would bring new interpretation" (ibid.). This lack of representation and knowledge was causing museums challenges, as the sites she approached wanted to do more to talk about disability but felt unable to do so since they lacked the specialised knowledge required. By collaborating with disabled individuals and disability-led organisations, the museums were empowered to approach this topic and had access to advice and lived experience, as was discussed within Chapter Six.

Kingston (2018), who worked for the History of Place as a curator, emphasised the fact she was drawn to the project as she felt it was a compelling story that needed to be told. She also stressed the opportunities it provided for experience in partnership: to work with volunteers and other museums, alongside Accentuate, and to fully explore the "richness of accessibility" at greater depth. For her, this work was both a benefit towards her future career, as it gave her new experiences which she would learn from, and also an opportunity to enable the staff within the museums to gain the knowledge and skills and to carry out a project that was focusing on accessibility – something that she would then be able to build on in future exhibits. As has been seen above, here accessibility was the focus of the story told from the very start, rather than serving as a later add-on to the exhibition. Concentrating on accessibility from the beginning enabled these exhibitions to be carried out in different ways, such as ensuring information was presented in multiple formats, and encouraged staff and volunteers to gain new skills that could be further developed in their future work. Building up these

skills would empower the museums involved to approach topics that they might otherwise have avoided, and therefore encourage the inclusion of disability within future exhibitions.

When museums find themselves short of time and money, they can be quite hesitant to approach new topics, especially ones that they are unsure of and which are potentially controversial.

> "We can't just let this kind of drop off the agenda, because I think unless we're really pushing it, it will. Because I think, when museums are up against like, tight budgets, deadlines, the first thing to go often is access and thinking about those more difficult stories that they're not entirely sure how to tell. So I think we need more projects like this, not less. But we need to have more of a sector-wide approach, sort of saying 'we really need to get better at doing this' really."
> (Fox, 2018b)

Fox highlighted the importance of really pressing to address these areas, especially at points when such work would be difficult. The new difficulties arising in this area will be discussed within Chapter Eight, which considers the future work done by museums regarding disability.

The History of Place project aimed to make it easier to tell these stories by providing budget and staff so that their partners "could take more risks and be more ambitious" (Fox, 2018a). This benefitted both parties involved, and encouraged museums to approach stories they were previously unsure how to tackle – something which had been highlighted as a cause of reluctance within *Buried in the Footnotes* (Dodd, Sandell, Delin and Gay, 2004). The opportunity for collaborative work in such projects serves to enable museum staff to develop new skills and benefit from lived experience. The chance of participating in such projects was a major motivator for the Museum of Liverpool's *Blind School* exhibition, which they entered into in order to learn and to tell the story in ways that they had not used previously.

Collaboration was also important to the timing of NDACA, although for a different reason. Those involved in the project spoke of the importance of getting records now, before those artists and creators who were involved in producing the work they were recording all passed away. Cowan (2019) spoke of the importance of capturing the

stories before they were lost, with six depositors passing away between the start of the project and its opening. Collaboration also offered NDACA the opportunity to challenge negative stereotypes around disability and to argue against the view that disabled individuals are a societal burden. Recording the stories that represented these circumstances was felt to be important, as the chance to tell these stories in a way that used lived experience relied on being able to talk to those involved.

Goals for the Audience

Alongside speaking to museum staff about their own motivation, and their perceptions of the motivations of the museums as a whole for holding these exhibitions, I also spoke to them about what messages they wanted visitors to the exhibitions to leave with. The answers to this centred around ideas of raising awareness and providing information about shared history. There was also a sense within some of the case studies of a desire to encourage a view of disability influenced by the social model, leading even to hope of political engagement.

For Kingston (2018), the key message was that the "history of disability is not just a specialist history", but instead one that impacts on, and is of interest to, all lives. This was echoed by Fox (2018a), who said that working with a site such as the Museum of Liverpool helped "raise the profile of disability history, and proves the exhibitions can be really popular as well, not just for a niche audience but to a wider market". For both of them, the goal of the exhibition was to show that disability history has a wider relevance, and to engage audiences who might initially have been dismissive of the stories that they were working to tell.

This is also shown in Cowan's (2019) interview, in which he spoke of his interest in the art that was held within NDACA's collection, explaining the resonance of the artwork created for the wider community.

> "The NDACA collection is filled with images that disabled artists painted when they went to art school, and the first thing they did was self-portraits, and the first thing they did was nude study, of themselves, which was clearly a big thing about owning, recapturing, representation of their body, and I think that

everybody, man or woman, old or young, has issues with the way their body is personally portrayed. Because there's a lot of explanation of issues and mortality and ownership and freedom and big themes, which I don't think are restricted to disabled audiences or disabled artists."

In saying this, Cowan is trying to draw clear comparisons between the work of disabled artists and issues that everyone engages with – showing that the work created is relevant beyond the disability community, and indeed beyond the art community: to be of interest to everyone by touching on universal concepts.

Cowan also drew on how widespread the Disability Arts Movement was in "consumption of British culture", with the Paralympic opening ceremony widely watched and disabled celebrities such as Liz Carr, Matt Fraser and Warwick Davis being well known. NDACA aims to give people ideas "about precedent, and past and history, and heritage" (ibid.). Rather than disabled culture being something obscure and irrelevant, the goal is to show the impact it already has on everyone's life, whether they have a disability or not. The challenge for the archive is to acknowledge both the differences and similarities: to try to serve as both a celebratory space for a particular group (Sandell, 2005) and also to welcome in others who may be less familiar with the story shown – to be a space both for the disabled community and also for everyone.

As the Museum of Liverpool exhibition was looking at their own community and local area, it gave the chance for the museum to provide local people with a "better understanding of their own towns and communities and the role disabled people played in shaping those histories" (Fox, 2018b). Alongside wanting to ensure wider awareness of disability history, Jones also emphasised the idea of achievement, both for disabled individuals and for the city.

> "The School for the Blind was incredibly pioneering, the second one in the world in Liverpool, and to get them to understand why it was set up in Liverpool, that it was driven by disabled people for disabled people, so it was very pioneering in that respect, but also a reflection of the city and its sort of pioneering spirit." (Jones, 2018)

To Jones, the School for the Blind is part of a larger history of the city, showing again the impact of disabled people on the local area. Rather than thinking of disabled people as something separate, it offered the chance to view disabled individuals as "intrinsic

members of your community for hundreds of years" (Fox, 2018b), who had had an impact on the landscape of the city and who shared a history with non-disabled people in the city, both in the past and the present.

As well as considering the history of disability, modern views and attitudes towards disability and the stereotypes that occur were seen as important across the sites. Jones (2018) spoke of "reflecting… people's attitudes towards disability today, maybe challenging preconceptions around that as well", using the exhibition in order to tackle negative views and deepen understanding. Showing the history of the Blind School, and re-evaluating what happened there, was seen as offering visitors new ways of understanding disability (Dodd et al., 2010, p. 103), challenging preconceptions – for example with the reframing of basketwork to emphasise the quality and worth of the items produced. Rather than simply presenting stereotypes, this work provided visitors with a new way of engaging with these concepts as part of the museum's wider social justice work.

Such reflection was mentioned by the Science Museum's McEnroe (2018), although she did so more subtly, saying that her aim "is just to provoke thought, if that doesn't sound too corny". Whilst acknowledging that it could sound trite, she went onto explain:

> "If you're trying to be very very didactic and to educate people, often it doesn't work, it doesn't really come across. But if you can perhaps challenge people's assumptions and you know, if they go away and think or maybe do a bit of extra reading or talk to somebody else about it or just re-think their assumptions a little bit then I would, that would probably be for me a successful outcome."

Without dictating a necessary conclusion to reach, the museum is aiming to get visitors to reconsider their views on these topics, challenging their preconceptions and aiming to spark their curiosity.

Whilst the Science Museum was subtle in its aim of education and encouraging new perspectives, NDACA approached the idea of political activism more directly. Their goal was to directly challenge stereotypes and show how disabled people had radically changed the agenda (Hevey, 2018) in campaigning for their rights and aiming for equality. Hevey wanted to increase an understanding of what disabled people had achieved in terms of rights, both for themselves and for other minority groups.

> "I want people to understand that disabled people in British society were… have been a massive contribution, positively, and I don't mean in inverted commas "supercrip", I mean by radically changing the agenda. And much of contemporary equality – the Equalities Act 2010 you know came out of new duties in 1997 which came out of DDA 1995, so a lot of the modern equality that we all talk about came out of disabled people's activism. And I think that disabled people… the empowerment movement, the arts one and the rights one, are massive and should be remembered. And they're up there with suffragettism, they're up there with the class struggle, they're up there with the, you know, not quite the miners' strike, because it wasn't as economically massive, but certainly I want people to come away thinking 'Wow. Disabled people changed the paradigm, changed the world. And have fought for kind of justice. And not, you know, sitting in back rooms in a kind of non-agency pity way. They claimed back their agency.'…"

This emphasis on agency challenges many stereotypes which disabled people face. In showing their story and achievements, NDACA rejects ideas of disabled individuals as passive.

However, Hevey went further in his goal for the audience, rejecting how politicians have portrayed disabled people within the media and how they have been treated by policy.

> "Disabled people should win. It's appalling how they've been treated. Especially under the Tories. So you know, straightforward it's going down, I mean there's Tory cuts, they've been appalling, and the structural… you know, as Thatcher did to the miners in the 80s, the Tories have done to the disabled people. They are the enemy now, you know the construction, the position as the enemy within, you know? I think you've got to fight that shit." (ibid.)

By addressing the treatment of disability head-on, and explicitly criticising the role of the government within such treatment, NDACA is taking an actively political stance in searching for social justice, expressing the attitudes and lived experience of the artists involved within the collection.

Rather than play into the negative stereotypes around disability discussed before, the aim of NDACA is to challenge those views and to cause people to think more positively

towards disabled individuals, including acknowledging their agency and empowerment. Cowan explained the impact of modern attitudes towards disability, and the effect of this on disability rights.

> "I think, a lot of the progress that the Disability Arts Movement commented on is going backwards slightly, due to austerity and the way we find ourselves in the economy, and one of these depositors said to me, she said 'disability rights, which obviously the Disability Arts Movement is commenting on partly, is three steps forwards, one step back, you never reach peak access, it's a cause that never ends'." (2019)

Whilst aware that there is a long way to go, and that the achievements of the Disability Rights Movement face challenges, those involved in the creation of NDACA wish to emphasise the successes which have occurred and encourage visitors to sympathise with the cause.

Rather than aiming simply to share a historic story, NDACA chooses to emphasise the continuing importance of the issues that are being engaged with. Hevey (2018) explained his goal for audiences:

> "I want people to think 'Yeah, I hope they win. I hope that lot win.' Which is always the essence of a good story, and for social justice".

In saying this, Hevey ties directly into the discussion of human rights and empowerment discussed earlier in this thesis, and explains his hopes that, by educating individuals on disabled people's achievements, it will be possible to shift attitudes and encourage greater political support for disabled people. To Hevey, the work that NDACA is carrying out aims to achieve political engagement, and to ensure support for a cause which is dear to him. This goes beyond education: to trying to encourage a political view and a change in attitude towards disabled individuals.

All of the museum staff that I spoke to made clear that their goals within the exhibitions were to change viewpoints, to challenge misconceptions, and to encourage visitors to look at things in new ways. The extent to which there was a political aspect to this varied between sites, but the importance of altering views was clear across everyone I spoke to. These curators held these exhibitions hoping and aiming to create changes in attitude among their visitors.

Responses

Audience Responses

Having considered the messages that the museums were hoping their audience would leave with, I now turn my attention to the response that was received by my case study sites in relation to their exhibitions. When speaking of their motivation, there was emphasis placed on the idea of challenging stereotypes and getting people to look at ideas differently with the hope of changing attitudes. Considering how audiences responded will help us to understand whether or not the sites met these goals.

The first thing that is significant is that a large number of people were clearly interested in the exhibitions, with NDACA getting over five million page views in under nine months, exceeding their targets (Cowan, 2019), and over 40,000 visitors going to the Museum of Liverpool exhibition, as Fox (2018b) explained:

> "…that's only in three months. So, you know, this is not a niche interest. If you have got it in your museum, people will go and look at it and find it interesting. We had good feedback so I think, kind of busting that myth, that actually this is only relevant to a small minority of people, is, is key in sort of dispersing that challenge I suppose."

People were interested in the exhibits and came in large numbers to visit them – which supports museums' attempts at approaching this topic, as it is something that the audiences wanted to engage with.

For NDACA, positive responses in the public were explained by linking this to issues that mattered to them.

> "People get rights. And in particular, if people can understand the artwork that can be seen in operating in a wider context, political agitation or you know, mediums and styles and themes that they recognise… and that's… that's high visibility, from all levels." (Cowan, 2019)

Visitors were able to connect with the stories that were being told, drawing on "natural curiosity about other people's lives" (ibid.). Using familiar faces helped grow the sense of familiarity, but both disabled and non-disabled people were intrigued by the stories

that were being told, because those stories were widely relevant and were felt to be interesting.

Positive responses were also seen in the press and on social media. Fox highlighted a number of positive social media comments, along with press interest: "…in Liverpool, we had like, BBC Merseyside or BBC North West, I think it was, came and interviewed us when we did our opening, and it was in their local press" (2018b). This again emphasises the fact that there was a broader mainstream appeal in what was being done. Jones (2018) explained that whilst there were an increased number of blind and visually impaired visitors, there were also a lot of non-disabled people who visited the exhibition.

> "Because the blind school is quite a well-known place in the city, and the building is mostly still there, obviously the chapel was demolished and moved, but a lot of people are aware of the building because it's been used as lots of different things over time as well. So I think it's just got a really interesting history for a lot of people, and of course disability history is of interest to everyone not just disabled people as well."

Although the exhibition was focused on the Blind School, that was a key feature of the local area, and so the history that it covered was not just the history of disabled individuals but also was felt to be a part of life for those who lived nearby.

Hevey (2018) explained that positive media for NDACA arose from emphasising the radical and political nature of the story that they were telling:

> "…the media's been superb. We basically, again, sell it on the radical stuff, if you're not careful people'll say 'Oh, play it safe, and try and get a sale', while I always say 'be radical and you'll get interesting take up'. So for example, *Design Week*, we were their lead story in mid-June or July, and I knew they were looking at it from the design of the anti-Trump campaign, so I said 'Well listen, look, we were there. This stuff is about the design of disabled [people] twenty years ago', so they went… and that… they have half a million Twitter followers. And that caused um… NDACA to trend on Twitter. And we were one of the top 100 tweets in the UK that week, so and then we got on the Independent, Times Educational Supplement, BBC Four Times, so I think people just thought 'wow, this bunch of disabled people and their allies, had a

fight about rights and left all this culture'. It's quite a story, you know, and I think… in this age where there's less, and there's Trump, and there's Brexit, and there's all this kind of shitty reactionary bullshit, that a kind of progressive struggle that was full of joy and wit and cleverness, and for rights, you know, it's what's not to like?! You know, in the kind of darkening times we are in, I think people thought 'thank Christ for that', it's a positive story and it's got purpose in it and it's a good story, and all hail disabled people for doing it."

This highlights how people are able to connect the stories that are being told with those that they are surrounded with. It is this empathy with visitors' own experiences of alienation that the NDACA archive is able to connect to, combined with a sense of success. Emphasising the relevance of these stories drove interest in the project.

Positive responses were also received at the *Wounded* exhibition in high numbers, as Emmens (2018) explained: "it's been fantastically positive and actually the evaluation… I remember we sat in the presentation and they sort of said this is the highest sort of levels they'd ever had for an evaluation". Feedback through TripAdvisor and email was also positive: "I remember sort of the third comment that I had… which… was someone saying they really liked the exhibition but it wasn't gory enough. And I thought oh okay, but honestly that's about the most negative thing I've seen." This positive response was also echoed by participants, showing that they felt they had benefitted from the collaboration and were proud of the end result.

The very small number of negative responses Fox raised surrounding the exhibition in Liverpool are also of interest, because they were from disabled individuals who either disagreed with the message of the exhibition or else felt that they were not doing enough in terms of access. This is important as it shows that people did have high expectations of the exhibition due to its topic.

"We tried to do something which was maybe impossible from the outset which was to make it fully accessible for a range of different impairments. We didn't want to focus on, say, this will just be a brilliant example of best practice for blind or visually impaired people, or this will be best practice for Deaf people. We wanted to try and cover all different impairments, but of course, doing that means some elements are going to be more accessible than others because of course you know… but we tried to find ways that the story could be interpreted

in a number of different ways. So it could either be interpreted for a visually impaired person using audio description, or using tactile models, or it could be also interpreted for a BSL user because the film had been interpreted and so had the text panels, and those kinds of things. So we tried to find different ways of telling the same story but in different interpretation methods. But you can never get it brilliant for everybody all the time." (Fox, 2018b)

Despite the effort that was made to ensure access for all, some visitors were unhappy that it didn't go far enough. That this was the direction of complaint is significant, as it shows that visitors generally approved of efforts to enhance accessibility, and simply at times wanted it to have been taken further than it had.

Knowing how the audience responded helps museums to decide on their next steps. For all three case studies, it is clear that the response to their work has been generally positive. Visitors, both disabled and non-disabled, are willing to engage with exhibits around disability, and non-disabled people are able to connect the stories told to their own lives. This shows that the exhibitions are able to have an impact and is encouraging when we consider future work – more of which will be discussed within Chapter Eight, as my focus shifts to unlocking what these museums, and the sector more generally, are intending to do in the future.

Staff Responses

Having considered the motivation behind the creation of the exhibits and the responses from the audience, I now turn to how the staff responded to the end product. The work was being carried out with ambitious goals, but the extent to which it was successful varied, with several of the participants pointing out areas of the final exhibits which were below their expectations. However, generally such problems were more on the practical side: issues to do with technology problems and limited funds, rather than relating to how disability was being represented.

A number of practical concerns about the exhibitions were raised. Kingston (2018) spoke of her desire to make the final finish of the exhibition more polished, but also highlighted the fact that the History of Place project allowed for iteration and adjustment to be made – for example a shortening of the audio tour when the first

exhibition's audio tour was too long. Also at the Museum of Liverpool, Jones (2018) highlighted issues with the braille guides which have been covered earlier, and also discussed a lack of accessible consent forms for elements such as oral history interviews. It is worth noting that these forms have now been put in place for future work. Cowan (2019) faced issues with the scale of digitisation and the difficulties of future proofing the work. As technology is increasingly used as a part of exhibitions, problems will arise – however, this will be true of exhibitions more generally and not solely those relating to disability.

There were also issues relating to the temporary nature of the exhibitions. Fox (2018b) explained the challenges caused by the temporary location, meaning they couldn't divide the sections as they would like, whilst for Emmens (2018) the flashing light at the entrance wasn't quite what he wanted. The short time period for the *Wounded* exhibition was another problem, with a "flurry of enquiries" (ibid.) after its closing. As in the case of *The Blind School* exhibition, was due to the opening of other exhibitions, alongside the limited time certain objects such as the Tonks pastels could be displayed. That the museums would have liked to continue with these displays suggests that they felt them to be successful.

Alongside these practical concerns, there were areas that some staff felt had been underexplored. Jones (2018) expressed that she "personally would have liked to know more from the pupils past and present, and about the life of the school", due to the fact she wanted to share people's stories. Similarly Emmens explained he would have liked to share more about old age, whilst explaining he managed to include more objects than he was supposed to.

> "Considering I got… one hundred and eighty objects on there and I was told we can't have more than a hundred, and I managed – I kept being told it's too many objects, it's too many objects, and I don't think it looked like there were too many objects so no, I'm happy with that." (Emmens, 2018)

Emmens was also bothered by the fact he had to almost immediately head onto another project, meaning he had little time to share his work, although he was able to publish a paper examining how time affected and was included within the exhibition.

Hevey explained that there was a lack of coverage of black disabled artists, many of whom had died before the collection was created, meaning much of their work was lost. He felt that there had been a loss of

> "…locally funded disabled empowerment, and I think that's affected the outsider, those disabled people who couldn't put together economic narratives which were invariably black disabled people, women disabled people, you know, working class disabled people and so on, you know so that's the bit I think… you know, it's grim. I think the Tories have been an absolute (and I'm gonna swear here) fucking disaster for um… for disabled people. So that's the bit I think we've discovered. That… so after 2012, the cuts really kick in and you can see… now there have been very successful arts movements – Unlimited is one, Shape does a lot, there's successful culture going on but it's more that kind of… lots and lots of poorer disabled people, have fallen away I think. So they're not producing art." (Hevey, 2018)

This political change was felt by Hevey to have an impact on what could be collected, meaning that areas were missed, and stories couldn't be told. While no exhibit can cover everything, there were still some areas that staff would have liked to see examined in more depth.

Cowan (2019) explained that for NDACA there was a wish that they had been able to do more involving volunteer participation and cataloguing, enabling people to tell their own story, and also to have created a more mainstream media product to ensure visibility. This highlights the importance of ensuring that collections are well known about, with media responses playing a significant role.

Despite this, the general response from staff was that they were proud of the end result and happy with what had been produced, the stories that were told and the preservation of archives that had occurred. Emmens (2018) expressed his relief "that it actually happened" despite delays in the funding, with high visitor numbers attending and loans including a painting that "hadn't seen the light of day" since the First World War. Kingston (2018) spoke of her pride in the fact that decisions were taken "with, not on behalf of, disabled people", using a range of consultations. This meant that she felt able to explain and justify decisions made, and gave her confidence in the final product. Collaboration was also a feature for Jones (2018) who spoke of the *From There to Here*

2014 exhibition, which involved working closely with disabled individuals and encouraging them to take decisions and express their personality. She felt this work helped to challenge assumptions in an accessible and welcoming way, drawing on "a big range of interpretive techniques" (ibid.) in order to convey the stories. She also highlighted training that staff received relating to the exhibition and the ongoing impact that this would have on what the museum was able to offer to disabled individuals.

For McEnroe from the Science Museum, the Medicine Galleries refurbishment created an opportunity to explore pieces of art, which was "quite a different thing for the Science Museum to be doing" (2018). Stepping beyond the expected topics to look into new but related areas and considering a more holistic understanding of health was something that this project offered because of the scale and size of the exhibition, creating a gallery expected to last for over ten years. The Museum of Liverpool's exhibition was far shorter lived, but whilst Fox (2018b) wished that it would have been possible to carry out bigger exhibitions for longer time periods, she spoke highly of creating

> "…what felt like, more like sort of permanent exhibition spaces in quite temporary situations and have that like, real quality, it just felt like they were all of the highest quality and completely in place in those museums, it didn't feel like a community initiative, it hadn't just been plonked in there, it felt very much like… that's what I was really pleased with, that it had that real professional quality to it as well."

This shows that, despite the challenges encountered, the end result was seen as a success, and something which belonged within a museum environment. Fox also highlighted the legacy that was created among those involved, empowering volunteers, creating networks and preserving archives that might otherwise have been lost.

Overall, staff feedback around the exhibitions was quite positive, with a sense of success surrounding collaborative projects and a view that many visitors had understood what they were trying to convey. This implies that the motivations of staff discussed earlier, surrounding the sharing of stories, was able to match up with the end results. The fact that staff were left with positive experiences may encourage them to take part in similar work in the future, and it is to future potential exhibitions that my attention now turns.

Conclusion

As has been shown elsewhere in this thesis, museums are increasingly viewing disability as a topic suitable for presentation within their exhibitions. This chapter has aimed to examine the motivations behind this, considering why disability is being represented and why it is being shown in the way it is. The chapter reveals an engagement with wider debates and discussions around the purposes of museums as a whole, as well as an awareness of the importance of telling a story which was felt to have previously been overlooked and to magnify voices that had previously not been recorded.

Museums are increasingly trying to engage with issues beyond their walls and to show that they can be socially relevant, in order to explain their purpose within an "unequal and divided social world" (MacLeod, 2018, p. 13). Including disabled individuals in a meaningful way in the creation and development of exhibitions, and reflecting that within the context of such displays, can help tackle some of the stigma and discrimination that disabled people are often affected by. Such work can also enable their success, and in doing so help to support disabled people in accessing their human rights. Ensuring that disabled individuals are represented is set out as a part of the UN Convention on the Rights of Persons with Disabilities, and this is something which museums are aiming to fulfil. However, legal obligation is not the only motivation driving this focus.

The engagement that is taking place around disability is happening for a variety of reasons, as has been shown within this chapter. For some sites, representing disability serves as addressing an absence, something which has previously been ignored from their collection and which they now seek to represent. For others, it serves as a part of the representation that they include and which they view as fundamental to their existence, and for yet other sites it is about sharing stories of interest to both the disabled community and those who are not disabled. Focusing on disability can also present museums with an opportunity to work collaboratively, and to learn steps

towards accessibility which can then be made use of throughout the site and within future exhibitions.

Tackling disability as a topic also allows museums to educate and challenge their audiences. Museums are able to use their work to teach: to highlight shared histories and raise awareness, as well as encouraging visitors to consider negative stereotypes, sharing the social model, and persuading visitors to rethink the views and expectations that they may hold.

This has all led towards work aiming to include disability as part of the richness and variety of humanity, something that should be considered and viewed as relevant. The work detailed here links to the changing conception of what the purpose and goal of a museum is, but also serves to emphasise that disabled individuals have stories that are worth telling. In doing this, the value of disabled lives and experiences is bolstered, and prejudices and preconceptions are challenged. Museums are increasingly finding that if they wish to be fully representative of their audiences, they must engage in telling these stories, and do so in a non-neutral way.

In my next chapter, I aim to address how museums are continuing to tell stories around disability, including it within a wider understanding of the diversity of humanity. I will also consider what guides displays of disability and what is being planned in future work, building on what has been discussed within the rest of this thesis. Stories around disability are being explored currently, but within the next chapter I aim to highlight what is seen by those working in the area as the likely next steps.

Chapter Eight – Widening the Narrative

Introduction

Last chapter, I examined the motivations of the staff who were behind the case study exhibitions chosen for this thesis. I uncovered why they considered disability a suitable topic for their work, whether because they were already tackling these issues or because they felt that it was something missing from their programme. I also showed how they benefitted from working collaboratively, and the passion that existed for sharing the stories around disability. Finally, I considered how they wanted audiences to respond to their work, and explored audience and staff responses to the sites.

My attention now moves to the change in how disability has been understood by museums, through the different methods that have been used over time, with disability moving from a topic that was widely hidden to something which is now increasingly viewed as part of humanity's diversity – and the related concept that disabled people's experiences have something vital to say regarding other broader topics. When asked about motivation, many of the individuals questioned spoke of disabled stories being human stories, and I will explore this now, reviewing both how disability is being integrated within collections and the next steps that are being taken by the case study sites.

These in combination will guide me to my final chapter, in which I examine what has been learned throughout this thesis, reviewing the key points and recommendations that have arisen as well as considering limitations that the project faced and future areas of work.

Integration of Disabled Stories

How disability has been understood and represented has changed over time, with perception moving from it being a case of individual weakness to an understanding that the cause of disability is the barriers that society has introduced. In this chapter, I will

argue that understandings of disability are beginning to shift again, with disability being more considered as a part of human diversity, and will evaluate the changes shown within how my case studies broach this topic. This shift will affect how representation of disability continues in the future, including the representation of this topic within museums.

My case study museums were increasingly working to integrate stories around disability within broader narratives which they were presenting within their collections. The level to which this was done varied between the case study sites, however across all three cases I found it present to some extent.

This is significant, as it shows an active effort to ensure that disability was not completely siloed off separately from other narratives, even when some exhibitions were only focused on disability – these exhibitions on their own were not considered to be sufficient in terms of representation, and instead the museum was working to include both integrated and separate approaches. The extent to which disability is separated or integrated within their exhibition will help to shape the messages and ideas that visitors leave with. Establishing a story of disability as something separate can encourage celebration of the lives shown, but can also be othering. Meanwhile, integrating a story can cause it to be missed, but links it to wider human experiences. A mixture of the two approaches, therefore, may provide a more meaningful examination of both disabled experiences and of what it is to be human.

Some museums have become increasingly interested in their social and moral role within their communities, as was seen in Chapter Two where I explored museums' movement towards becoming more activist with society, addressing issues surrounding rights and discrimination head on. There is a growing awareness across all sites of the importance of considering different experiences and representing the lives of a range of individuals rather than providing one single narrative of what has occurred. Work is also ongoing to try and link the stories told by museums to the experiences of their audiences, as will be seen here.

The Science Museum's new Medicine Galleries are their largest exhibition, showing the importance that they are placing on this story and topic. Within these galleries, stories,

objects and images relating to disabled individuals are integrated throughout. Stories about medicine are not always pleasant; however they are something that everyone can relate to, as health is a part of all our lives. The new Medicine Galleries were conceived to try and encourage such connections. For the Science Museum, sharing stories about disability meant acknowledging the complexity of medicine and the way that the changes which have occurred were not always what might have been expected. As Emmens (2018) explained regarding the *Wounded* exhibition,

> "I actually met an Afghan veteran on these amazing 20,000 pound limbs, who's got a split hook which is pre-First World War patent. And he said 'Well I tried a fancy hand, but this… this does the job, this works a lot better.' So there's not that… straightforward trajectory of more that… the more technically complicated means its better. And there isn't that easy solution, even though you've got all this raw material to work with, all these people bleeding to death you know, it takes an awful lot of mistakes and luck, and that's another thing – I really want to get over that… that's why all the lucky charms were partly in there."

Despite developments in technology, this veteran felt more comfortable continuing to use a split hook with a design that was over a century old, as it was able to provide him with the function he needed. Medicine isn't always a path from historic 'primitive ideas' to more modern technological solutions, it isn't always a victory, and a lot of it relies on luck. By acknowledging that diversity of experience, and the factors that were outside of scientific control, the museum was attempting to more honestly convey the experience of those who were affected by the wounds the exhibit was titled after. This was also conveyed within the Medicine Galleries, and with their accompanying publication *Medicine: An Imperfect Science* (2020), which acknowledged both the achievements and difficulties of medicine and so transformed the story from one of simple triumph to something more complex.

This complexity is something engaged with by Ott (2010), who explores how objects can be used in order to engage with multiple narratives. She highlights the way that museums can serve as places where individuals can reframe what they know, using the tactile nature of objects (ibid., p. 272). By engaging with the material objects of disability – such as this split-hook hand – an individual visitor is able to consider what it would mean to the user and to challenge preconceptions that they might hold.

Examining objects related to disabled lives, as enabled by these exhibitions, can help to unlock deeper understanding and learning, as well as potentially creating an emotional response which helps deepen the visitor's comprehension and improve their experience.

The new Medicine Galleries at the Science Museum foregrounded collaboration, with several co-created displays and the incorporation of many images of disabled people, designed to challenge people's conceptions. These collaborations included photographs created by Sian Davy for the project "When medicine defines what's 'normal'" (Science Museum, 2020b). This project consists of life-sized portraits and interviews that aimed to present diverse experiences and which are spread throughout two of the new galleries, peopling the space with bodies and minds outside of the perceived norm. This again challenges preconceptions a visitor may hold, but does so in a way that prevents othering and encourages a reconsideration of what the visitor expects.

While Emmens (2018) was dealing with vast stories that crossed huge swathes of the population, both in *Wounded* and in the Medicine Galleries in which he was working on the theme of public health, he was still working on making the information accessible and familiar – "a lot of it is that sort of zooming back and looking at cities and you know, things on a bigger scale", focusing on vaccination drives and other larger-scale scientific issues. By focusing on a large scale like this, Emmens felt he could both address the number of people affected and also link it to the lives of visitors, again connecting medical issues around disability with the broader human experience. The emphasis shifts from medicine being something that affects only the lives of the sick to something that affects us all – an idea with added resonance at the time of the coronavirus pandemic which spread across the world in 2020, which has brought issues of health and disease to the forefront of politics and social life and will be touched upon again in my conclusion.

For the Museum of Liverpool, integration of disabled objects is something that has been carried out since the site's founding, as the museum was formed with the idea of ensuring "content relating to different kind of communities [was] represented and embedded across the whole museum" (Kingston, 2018). This resonates with Sandell's (2005) pluralist approach to difference, in which museums make an active effort to include and integrate a range of stories.

Representation of disability at the Museum of Liverpool includes a trail relating to disability through the museum, as well as objects being embedded in displays and their links to disability history emphasised. Work has also been done to acknowledge potential problems and challenges around the stories being told – for example, a case of historic abuse was included, as Jones (2018) explained:

> "…there had been an allegation of historic abuse from one previous… pupil, which had been in the press, not at the same time but earlier, so I think that made the school quite wary and they were probably understandably worried about what we were going to say in the exhibition. So we had quite a few discussions as part of the content team, and we wanted to acknowledge this, we didn't want to kind of pretend that it had never happened but at the same time you've got to think these are our key partners, the exhibition is about their school, about their pupils, they're loaning us all sorts of objects, so we decided that one of the pupils referenced the allegation and talked about that member of staff in his oral history interview so it was referenced in the exhibition, it was included. Which we think was the right thing to do but it was important that it was his point of view as a pupil."

This example shows the careful work that needed to be carried out in order to give an accurate exploration of history: addressing complex stories and accepting that individuals from minority groups are "complex human beings who might have… committed unsavoury acts, or been flawed in some way" (Ott, 2010, p. 270). Acknowledging past abuse and challenges was an important part of the work being done – this can also be seen in the acknowledgement of the limitations the school imposed, which were previously mentioned within Chapter Five of this thesis. Allowing complexity and nuance to shine through in this work both adds depth to an exhibition and allows for more challenging stories to be told.

Both the Science Museum and the Museum of Liverpool are taking care to integrate stories of disability throughout their work. NDACA, however, is proudly segregationist – it is telling the story of disability, and using works of art created by disabled people to do it. This is the project's mission: rather than looking at a broader topic, it exists in

order to share this particular story, and in doing so highlight the impact and achievements of disabled individuals, as discussed within Chapter Five.

Even so, NDACA has been making an active effort to link the stories that it was telling to the lives of non-disabled individuals, as Hevey (2018) explained:

> "For example, *Design Week*, we were their lead story in mid-June or July, and I knew they were looking at it from the design of the anti-Trump campaign, so I said 'Well listen, look, we were there. This stuff is about the design of disabled [people] twenty years ago', so they went… and that… they have half a million Twitter followers. And that caused NDACA to trend on Twitter."

While the story that NDACA aims to tell is very much focused on the lives of disabled individuals, an effort is still being made to emphasise its wider resonance and broader appeal, and judging by the response from the public this process is currently rather successful.

The work that NDACA is doing interlinks with work done by Kudlick (2003) which argues that disability is "so vast in its economic, social, political, cultural, religious, legal, philosophical, artistic, moral and medical import that it can force historians to reconsider virtually every concept, every event, every 'given' we have taken for granted" (p. 767) – that to consider disability requires a reconsidering of any number of our understandings.

By incorporating disability in a broader way, it becomes possible to integrate disabled perspectives within a wider narrative, rather than continually focusing on centralising non-disabled viewpoints. Disability raises questions of citizenship and community values, and shapes understanding of what society means and is able to mean (p. 781), and can only do so if approached with respect and care. The links that NDACA draws between the work of those involved in the Disability Rights Movement and broader equalities movements shows such work in action.

Within Chapter Three of my thesis, I investigated how popular culture has represented disability, emphasising the importance of realistic portrayals (Garland-Thomson, 2010) and considering how these were slowly being added to the current representations, with characters in soap operas and the like being developed beyond their disability. Including

characters who have disabilities simply as a part of the story, rather than their disability being the story's focus, is something which seems to increase people's perceptions of what disabled individuals are capable of. In the same way, including disabled people throughout museum exhibitions, rather than simply within those that feature disability, offers a chance to widen understanding and connect to broader narratives.

Humanity is broad, and encompasses both disabled and non-disabled individuals. As was shown across my case studies, stories around disability attract widespread interest, because they are human stories, with aspects that resonate with all lives, not just those of disabled people. Acknowledging disabled individuals as a minority group, with rights that need to be respected, but also accepting their humanity is important – for disabled people's perceptions of themselves, for non-disabled people's view of disability, and for everyone's understanding of what it is to be human. Such understanding cannot necessarily be reached if disabled stories are always cut off from the broader topics that museums aim to address. Instead, stories of disability at times need to be considered alongside other narratives.

By setting out the difference between integrationist and separatist viewpoints, I am not arguing that one is better than the other. Indeed, rather than being entirely integrationist or entirely separatist, stories told by museums are often somewhere in between, and there are benefits to both attitudes. However, I hope that I have highlighted how these two methods can be used to achieve different goals.

Disability and Diversity

As was seen within Chapter Three, disability had previously been seen as something that museums were cautious about displaying, for fear of recreating the freak show and encouraging unwanted staring. Indeed, in Dodd et al.'s *Buried in the Footnotes* project (2004) it was found that many museums held objects related to disability, but didn't necessarily know what to do with these objects beyond "limited, often reductive and stereotypical" representation of disabled individuals as passive victims (ibid., p. 13). This work was carried out almost twenty years ago, and uncovered a lack of curatorial knowledge as well as concern about approaching the topic. However, this project also

discovered that curators were apprehensive about misrepresenting disability and wished for guidance, which the project aimed to provide. Potential challenges were addressed (ibid., p. 17), and museums involved in the project were encouraged to use the voices of disabled individuals and address the social model. My initial aim within this thesis was to investigate how things have changed over the past decade and a half – how museums have learned and gained in confidence. The fact that the case studies I am addressing felt able to include disability within both focused and integrated narratives proved that change has occurred.

I also argue that integrating disabled stories within broader narratives is important for those who are represented – people may be disabled, but that doesn't encompass the entirety of their identity. During an interview with Cowan (2019), he explained that individuals do not belong simply within one category.

> "What do you define yourself as, or do I define myself as? Am I white? Am I male? Am I somebody with Parkinson's? Am I an archivist? Am I working in the media?"

To try and separate disabled people off in this way can be exclusionary, and does not fit the way that people view the world. Disability may form a part of an individual's identity, but it is not the whole of it – as a queer disabled woman, I find that stories which ignore intersectionality overlook key parts of who I am and how I interact with the world. Rather than continual subdivision, Cowan argued for both an understanding of unity, and also the need for acknowledgement of the experiences of different groups. By acknowledging all aspects of their identity and taking an intersectional approach, a richer, more realistic and more meaningful understanding of an individual's life, and of society, can be developed.

Within the case studies I examined, disability was something included in both broader narratives and within disability-focused displays. This achieved a deepening of understanding, drawing out links to wider narratives while ensuring that key moments of history were celebrated. The sites appeared to be more confident around the handling of disability, and to have moved on a long way from those examined by Dodd et al. over fifteen years before. My attention now turns to what will come next.

Future Plans

So far in this chapter, I have considered how museums are integrating and segregating stories around disability, emphasising how they are working to centre disabled voices and to also show disability as fitting within the broader narratives that they are exploring. I now move on to take a final look at my case studies, considering what their future plans are, and how these integrate with these two key findings. This will lead into my final chapter, which considers the future of the sector as a whole.

Firstly, it is important to consider what it was that the museum staff felt that they had learned from taking part in the exhibitions I have examined within this work. A number of those spoken to highlighted the opportunities that the work had offered to help them learn more about disability and its representation. Kingston (2018) explained that being involved had taught her a lot about access needs and the benefits of collaboration, but had also shown her the importance of "being brave and having high ambition", even when the budget wasn't particularly large. By being allowed to take risks, she felt that the end result was of higher quality than might have otherwise been achieved. Jones (2018) reflected on how the exhibition had her thinking in new ways about what was offered at the museum, and how they engaged with different groups outside of the museum, embedding that throughout all their work rather than just for projects focused on disability. The projects detailed enabled Liverpool Museum to form new connections and make links with a wider audience than before, and the staff involved intended to continue with this work.

The Science Museum was able to use evaluation of the *Wounded* exhibition in the development of the new Medicine Galleries, building on prior successes surrounding participation projects, including working with an access panel to check panel text (McEnroe, 2018). Research from previous exhibitions which showed that it is important to have representation of different groups visible in the gallery was used to inform the Medicine Galleries, with life-sized portraits to ensure all types of people were visible throughout – "different bodies, different ages, different physical characteristics, so it's something that you'll immediately see, but they are beautiful portraits in their own right" (McEnroe, 2018). The beauty of these portraits is a long way from the criticism of early drafts of *Wounded*, claiming that it showed "all the horrible things that can

happen to someone on the battlefield" (Emmens, 2018), as was discussed in Chapter Seven. Images in the Medicine Galleries weren't displayed to evoke horror or pity, but instead as a part of human diversity. Emphasis was put on the humanity of those depicted, and work was carried out to explain their stories in their own words.

Emmens (2018) at the Science Museum felt he had learned more about how prosaic, everyday objects such as a packet of cigarettes or a hot water bottle could be used to powerfully and impactfully tell a story. He also explained that he had learned that people could engage emotionally with exhibits:

> "…a lot of people found it really moving… people have cried in it, or got very upset in it, but not in a… running away screaming kind of way, and that's quite a powerful thing. And I'm not saying that's because of what I've done. I think it's because of the nature of the material, but… you know, it's… it's sort of gratifying to know that you can engage to that extent. You know, I think watching a film or reading a book… outside of real life, that's what this sort of thing can… do that sort of stuff so it's quite… it's… sort of reassuring that that can, that an exhibition can do that."

This shows a move towards allowing and encouraging emotion within the museum space, addressing difficult stories and acknowledging that those who are witnessing them may well find them challenging, whilst trying to handle them respectfully. This links to the emotional learning discussed by Ott (2010, p. 276), as visitors respond empathetically to what they are shown. Addressing complex issues, and not necessarily presenting an answer, is something that Emmens felt he had learned from the work carried out within this exhibition.

For Fox at the Museum of Liverpool, as well as those involved in NDACA, the work was approached from a position of already being deeply immersed in the ideas surrounding disability rights, and so what was learned was slightly different. Fox (2018b) felt that it enabled her to argue that disability-focused projects have an appeal for a more general audience, and encouraged the museums that participated to look at their own access guidelines, especially around the creative use of audio. She was able to show that there was a demand and an interest in the work she was carrying out. Another thing that she had focused on was encouraging the museum partners to

> "…look towards Deaf and disabled people to sort of, lead this sort of work as well, and if you're going to have tours or guides, make sure you're involving disabled people in doing that, make sure you're not just using non-disabled staff members that really don't know what they're – they just don't have that personal experience to share. And I think that's something that we tried to impart – wherever you can, use disabled people to tell these stories, get them involved in doing guides and tours and workshops."

Encouraging museums to act in this way links to the idea of "Nothing about us without us" discussed earlier in the thesis. However, she also pointed out that the museums that were taking part in this work were already open to this kind of concept, as they had come forward seeking the collaboration. This raises questions of how more reluctant museums can be encouraged to engage with the disabled community – something she was keen to take forwards within her next steps.

At NDACA, Cowan (2019) spoke of learning about the Disability Arts Movement, but also about the importance of broader engagement:

> "…the [higher] level of access you can provide to everything in our archive, including the things that are quite often regarded as private to the archive like the catalogue, the better. And the more… the more people you can engage from your target audience, and from other audiences, the better. It's harder to close something, or for something to be rubbished, if there's lots of people engaged in it, who feel that they have a stake in it, who are interested in it…."

If the project is to be successful over a longer time, it has to relate to a story that people are interested in and willing to engage with. This did indeed seem to be the case in the work done by NDACA. The site emphasised its story as one of protest against injustice, and this seemed to have an interest that was universal, and caused engagement far beyond disabled communities, as Hevey (2018) explained.

> "Middle class people are getting poorer, you know, migrants are being blamed, the working class are alienated, the jobs are shit, everyone's got a portfolio career of crappy pop-up jobs you know? It's obvious, there are tens and tens of – the majority is alienated. And when other alienated people fight back, successfully, people like it. So that's what I think it's tapped into. A zeitgeist of alienation in the village, you know?"

The political story of the Disability Arts Movement was found to have a far wider resonance with society as a whole. This again emphasises how disability is a part of humanity, and how the stories these sites tell fit within a wider social and political landscape.

As well as taking forward what they had learned from this work, all three of the case study sites were considering ways that they could continue involving representations of disability within future displays, with plans already in place for what they were going to do next on this topic.

The Science Museum was working on a vast redevelopment of the Medicine Galleries, which opened during 2019. Whilst within *Wounded* Emmens (2018) had initially been reluctant to carry out participation projects, as shown last chapter, he had become more confident with them as a way of working, learning that they "can be very successful". He explained how he was working with those affected by mental illness to try and tell challenging and difficult stories in the Medicine Galleries.

> "We've got lots of interesting objects from asylums and what… what were the old asylums, so some of those are featuring and we've got… we're having a… I can tell it's going to be quite controversial again, we're having a padded cell reconstructed, with some interpretation we're working on now, but within that there's also this… the output of the participation project will be a series of animations which this group is working on with a filmmaker, so within this sort of slightly more straightforward presentation of the old asylum system is this… more contemporary take on mental health, by people in the system."

Using disabled individuals' voices is important when tackling such a potentially challenging and emotive subject, and Emmens appeared to have gained ability in this work. He was aware of the potential issues that could arise from the display of the padded cell – having been warned of potential controversy by Bethlem Museum of the Mind - but wanted to use it in order to explore new stories, and to do so respectfully. A participatory approach was important in achieving these goals.

NDACA as a project was coming towards the end of its main phase whilst I was carrying out my research, with the archive wing open and much of the material already collected. Hevey spoke of his difficulty in ensuring that the project was sustained, both

over the ten year contract held with HLF, and also into the future, using a simple model and creating "a low-cost digital museum in cyberspace" (2018). At the same time, however, the staff were eager for it to become an "internationally-used resource" (Cowan, 2019), taking advantage of its digital presentation to encourage global "academic engagement with a unique collection". Cowan also highlighted "a similar but different lottery project planned, which will be hopefully a history of the disability rights archive, a history of the rights movement that the Disability Arts Movement paralleled". This was undergoing funding bidding at the time of my interview with him, and has since been funded, meaning that the work will go ahead.

Shape Arts, which was responsible for the delivery of NDACA, is also working far more widely in the disability cultural sector, with Hevey explaining

> "…the trick is to build a series of steps, stages that creatives… disabled and barrier-facing creators can take, so that's what we do. We make sure that a starting out creative knows how to start working with Shape, right through to breakout international work, and learns the stages of a career, and then we can help them on the stages of their career." (Hevey, 2018)

By slowly building up support from early on in an individual's career, the goal is to encourage disabled talent. This is quite a separatist view but, as is discussed above, such an approach is not necessarily negative, and may well be needed in order to combat the unique barriers and challenges that disabled artists may face.

Although the History of Place project ended after *The Blind School* exhibition, all three staff members involved intended to take forward what they had learned. For Kingston (2018), access had become more of a priority – whilst previous exhibitions had met DDA requirements as discussed by Smith et al. (2012), her goal for future work was to improve upon this, ensuring signposting and braille booklets even in cases where disability was not the focus. She was also working on a future exhibition at the Railway Museum, examining the dangers of employment for the railway companies at a time when their view was that it was "better to pay for prosthetics than the safety equipment" (Kingston, 2018), and she was hoping to work alongside a disabled curator in this project.

Working with disabled individuals was also important for Jones (2018), who was working on a "really powerful exhibition" in partnership with Wicked Fish considering "how organisations in the city like laundries exploited people with learning disabilities, when they worked in these institutions", addressing a potentially challenging story and working with disabled people throughout. Fox (2018b) addressed the issue more widely, explaining that in her view there needed to be "more of a sector-wide approach" – similar to that spoken about by Hevey. Her next project was focused on addressing the "huge underrepresentation of disabled people working in museums in particular, and particularly in curatorial roles" (ibid.), encouraging and supporting disabled people in working in the sector, to provide new insight and new interpretation. This includes the formation of a training programme for disabled curators. She hoped that this would encourage museums that might otherwise be reluctant to move forwards in this work.

The issues raised here are particularly significant at a time of increased hostility to the idea of identity politics, as alongside the rising role of 'culture wars' in which the very purpose and nature of museums is heavily contested online and in Parliament. As was shown within Chapter Two, an increasing number of people feel that museums need to be socially purposeful, and I believe that it is important that disability is not overlooked in such work. The reasons for such absence in museums have been considered, but it is critical to ensure these stories are included – both within separate spaces and within main galleries.

There is growing awareness of the importance of hearing a range of voices within the museum sector, and numerous projects are being carried out to try and ensure this. However, Fox (2018a) explained the impetus she felt to try and ensure such projects around disability continued being carried out, and how much more there was to do:

> "We've only really scratched the surface over the past three years with what
> we've done. So there does need to be sort of concerted effort to maintain that
> kind of, to maintain it in people's minds as well and to keep it as a priority."

At a time of funding cuts and widespread debate within the museum sector, work around disability could easily fall away. However, this thesis has shown that it is important that that is not allowed to happen.

Showing stories around disability is important for disabled individuals, enabling them to connect with their own history and to understand links with the past. At the same time, it can serve to challenge stereotypes held by non-disabled individuals, increasing awareness of the barriers that disabled people might face and encouraging new ways of thinking. For all people, stories around disability raise questions about what it is to be human, highlighting achievements and making connections, and providing a more accurate understanding of who we are. Alongside this, such stories show the broad nature of humanity and the diversity and range that can be found within and across societies. These three case studies are succeeding at putting this into practice, and in the following chapter I will consider what the sector can learn more broadly from this work.

Conclusion

This chapter has served as an exploration of disability's place in the museum today and into the future, examining how it is more represented both as a difference to be celebrated and as a part of humanity to be integrated with wider stories. Disability is increasingly seen as worth considering, not just as a specialist topic but something that has significant resonances across the breadth of humanity with stories that matter to a large and varied audience. The case study museums are all intending to continue with their work around disability, feeling it is valuable and important, and this ties to earlier discussions of museums and social justice and the treatment of other minority groups. As shown within Chapter Two, museums are not neutral. The stories they tell have an impact, and by considering the lived experience of the diversity of humanity, they are able to both improve their offerings and better serve their audiences.

As I have worked with the case study sites, I found that they have gone beyond simply considering disability as an overlooked history. They are increasingly viewing it as a story that is of relevance across society – a story that they wish to integrate so that both disabled and non-disabled audiences are able to learn from it, and to be challenged by and to celebrate disabled lives, as an integral part of the tapestry of humanity.

Due to the nature of the case studies I was considering, I intentionally picked sites that were working on a disability-focused project, as was shown within Chapter Four. This

was done in order to ensure that I would have material to discuss. However, what became clear to me throughout this work was that for both the Museum of Liverpool and the Science Museum, they were going beyond these disability-specialist exhibitions and integrating disability within their main galleries. At the same time, NDACA, whilst focused on the stories surrounding disability due to its remit, was trying to ensure that those told were widely listened to, drawing links to relevant social movements and emphasising how this is a story that is relevant for all. The stories that these museums were telling had far wider resonance than simply the disabled community, and all the case studies were working to reinforce this.

Having considered the next steps of the museums I have used as my case studies, I turn my attention to a wider understanding of what is next for museums surrounding the representation of disability. I will be giving recommendations and emphasising the key points that have arisen, and acknowledging the limitations faced by my work, as well as highlighting future questions that could be addressed regarding the topic in future research.

Chapter Nine - Recommendations and Conclusions

Introduction

I began this thesis because I wanted to develop a greater understanding of how museums are addressing their exhibition of disabled individuals and stories. In the decade and a half since Dodd et al.'s groundbreaking *Buried in the Footnotes* (2004), discussions around disability have changed. I wished to explore these changes, and to examine how museums in the UK are now approaching disability. As shown throughout this thesis, the concerns and issues which guide both disability studies and museum studies have a great deal of overlap when it comes to the representation of disabled individuals within museums. Both are concerned with representation of and by disabled individuals, and both focus on questions of social justice. I therefore drew on both disciplines in order to create this work.

I discovered that the representation of disabled individuals is a topic of growing importance for museums, and one which they feel under pressure to do in the 'correct' way, wary of causing offence, upsetting audiences, or misrepresenting the truth. Although some museums still struggle to approach the topic, there are examples of good practice, some of which I have analysed within this work. These examples of good practice are driven by two key elements:

1. The inclusion of the voice and expertise of those with lived experience of disability.
2. The representation of disability as part of the rich fabric of human diversity, rather than as something separate and shameful.

The first of these goals was examined in depth within Chapter Six, which considered how the case study sites made use of participation and collaboration. The second was discussed within Chapter Eight, which looks at how the stories being told are integrated with wider ideas by the museum staff. The use of the social model has assisted in ensuring both of these goals are met: using a model more acceptable to disabled individuals means that they are more likely to participate, and the social model's

emphasis on barriers caused by society helps disability to be viewed as a part of humanity, by drawing links with other marginalised communities and the prejudices that they may face. Whilst the social model is rightfully criticised by some for oversimplifying disability, as an initial way of explaining disability to a wide audience, it appears valuable because it challenges negative stereotypes around disability and offers an alternative understanding to the medical model which is widely seen within popular culture. Through working with disabled individuals, museums are able to create meaningful displays which integrate rather than alienate those they are representing. Such integration makes use of the expertise available and also shows these participants as a part of humanity.

This concluding section of my thesis aims initially to restate the purpose for which the research was undertaken. It then sets out the key arguments that have been made, before considering the limitations of the research and the contribution it provides to knowledge. Finally, recommendations are given and closing remarks made. Through examining and critiquing these three case studies, I hope to contribute to future work to be done by museums around the representation of disability.

Restatement of Purpose

This research was carried out in order to examine an area often overlooked within discussions of equality – that of representations of disability. I began with two main research questions:

> How are disabled people and stories of disability currently represented in exhibitions and displays within UK museums?
>> and
> Which factors, aims and concerns shape these narratives?

Building on these, I developed a series of further research questions to shape the rest of my research investigation. These questions were split into two groups; the first considered the nature of representation within museums, including objects held and the

stories that were told over time, while the second focused more on the views of museum staff and the aims of the exhibition. The first set of these questions could be answered mostly by an examination of the sites themselves, while the second set relied on interviews with staff and discussion of their motivation. Using these two sets together, I was able to gain a more holistic understanding of the stories that were being told around disability, and the reasons for these.

All of the research questions used were founded on a belief in the importance of representation. This means that I believed from the start of this project that it was vital disabled individuals could see themselves reflected within museum collections. This thesis was conceived with a focus on the importance of social engagement, and supported by work done by museums around other underrepresented groups. I approached the project with the idea that museums are not neutral, and that whatever they choose to include (or discount) from their exhibitions sends messages to their audiences. These principles continued to guide me throughout my work. My questions were also drawing on research within the field of disability studies, such as the idea of "Nothing about us without us" (Oliver, 1992), as I aimed to combine the two areas of museum studies and disability studies into a thesis which drew on both.

Thesis Structure

This thesis began with setting out the aims and guiding principles discussed above. I then turned to existing research, with two literature review chapters – one focused on museums, social justice and human rights, and the other considering the representation of disability within media and its impact on disabled lives. The final theoretical part of my research was an examination of the methodology that would be used. Having established the theoretical underpinnings of my work, I then moved onto a more practical and case-study based section of the thesis, in which I analysed findings in order to come to my own conclusions about the current state of disability representation.

Within these findings-based chapters, I was able to explore how the case studies I was examining were able to represent disability to their audiences. I considered how disability was represented, and how that served to welcome rather than 'other' disabled

individuals, before turning my attention to participatory projects and the range of methods that could be used in order for the lived experiences of disabled people to be heard and shown within the gallery space. Next, I examined the motivation of the creators of these exhibitions, evaluating why these exhibitions were being held and the responses of the audience. Finally, my focus shifted to the future of disability representation within museums, outlining my key themes and assessing what had been learned due to this work. Within this conclusion, I am drawing together all I have learned from this project, with the intention of developing recommendations to guide future work and acknowledging the contributions that my work has made to knowledge.

Key Arguments

The key arguments developed as a result of this research were the importance of the inclusion of disabled voices and the need to represent disability as part of diversity rather than always separating it off into specialist-focused exhibitions. These interpretations relied on finding areas of collaboration and agreement grounded in disability studies and museum studies.

My research emphasises the importance of including disability as something which can be highlighted by specific exhibitions, but also something which can be enfolded seamlessly within the body of wider stories – something that can be acknowledged without needing attention drawn to it. As Kudlick (2003) argues, disability underpins much of social history, and so should be included within these stories. Such varied presentation is important, as by presenting disability as just another factor of diversity, disabled individuals can be included within broader understandings of humanity.

When disabled individuals are always considered separately from other people, without the links between their stories and those of non-disabled people being shown, there is a risk that they find themselves pushed to the margins, viewed as in some way sub-human and undeserving of respect. Disabled individuals have often historically been treated as research objects rather than individuals in their own right (Snyder and Mitchell, 2006), and have been closed off from broader humanity and faced with dehumanising stares (Garland-Thomson, 2000b). However, if representation of disabled individuals is only

included within broader stories, they may be overlooked. There is a benefit, then, in ensuring that both methods of representation are used. This enables disabled stories to be celebrated, but also to be included naturally within other narratives. Disabled people are, and have always been, a part of humanity, with disability historically being widespread (Ott, 2005). The stories told around key themes should therefore include disabled people simply because their inclusion gives the most honest and accurate account of the events. It also serves to challenge modern stereotypes and increase understanding and empathy.

The importance of incorporating disabled voices has been shown throughout this thesis. I have argued that letting people be heard can be empowering and also provides a more truthful understanding of experiences, alongside highlighting elements that might otherwise have been overlooked, as could be seen within the selection of objects for the Museum of Liverpool. As Garland-Thomson (2009) shows, disabled people can be given power by controlling how they are presented, and by doing this they can successfully intervene in non-disabled people's stereotypical views of disability. Providing the opportunity for both space and inclusion will allow for a more effective and honest representation of disability than has been seen before, and such work may well also be relevant for other marginalised or overlooked groups.

My key argument from this thesis is that disability needs to really be understood as a part of what it is to be human. All individuals will experience impairments at some point in their lives and find themselves facing barriers caused by a society which has not tried to account for these impairments. When we use museums to tackle big questions, disability needs to be considered – to be highlighted and to be enfolded and to be present. To be human is to live with disability, to live alongside disabled people, and to play a part in disabled stories. If museums want to tackle big themes and issues affecting the world now or in the past, disability will be present there, and these connections can benefit both from being emphasised, and from being included without fanfare.

Limitations of the Research

There are limitations to what has been achieved in this project. As a small-scale study, my work was focused and situated within my three cases. As addressed in Chapter Four, this could potentially limit the generalisability of this information. However, I drew on a number of cases and contextual examples in an attempt to try and ensure as much as possible could be learned from these specifics. Through careful selection of the cases and triangulation of evidence, I believe a great deal can be extrapolated from these examples for the sector as a whole, as I have chosen to highlight good practice (Denscome, 2007, p. 61). While the techniques here may not necessarily be found within other sites, it serves as a useful guide for anyone who wishes to approach such work.

A further difficulty was the challenge in showing the full richness and complexity of the cases within this thesis, especially when as a researcher I am inevitably working from within my own positionality. Although this allowed me to have some insight into the experiences and attitudes of disabled individuals, it also posed potential difficulties, as I would bring my own views to my work. The individuals I interviewed for this thesis were extremely engaging, and I have aimed to allow their own words and voices to be shown throughout this thesis. In this way, I hope that I have represented them fairly, and done justice to their work. I also offered them the opportunity to cross-check their data, although due to other commitments this often wasn't taken up by the participants. Throughout this work, I have tried to be driven by the data and to move from this to my results; however my own inherent biases could have impacted my conclusions. I believe such interference was kept to a minimum by careful analysis of the interviews, and by examining the surrounding literature. Nevertheless, I acknowledge it would have been impossible to remove my own biases completely, as my goals and aims have directed the work throughout (Walshaw, 2008, p. 322). Research serves as a performance, with the individual researcher choosing for themselves which areas they feel are worthy of examination. Despite this, I hope I have shown the wider value in the area I have chosen to research.

A further challenge that I faced during the period of my PhD was the coronavirus pandemic, as discussed within the Methodology chapter. Although it struck after I had

completed my fieldwork, it required a restructuring of my writing process and limited my access to libraries, study spaces, and other students at a time when they would have been helpful. It also disrupted my routine, and created other commitments which affected my ability to work on this project. However, with support I have been able to complete my thesis. An additional complication arose because the case studies I examined were all carried out using in-person collaboration. It is too early to see how such work might alter in the aftermath of the pandemic, and this remains a rich area for potential future research, as will be discussed shortly.

Contributions to Research

Despite these limitations, I believe that this project serves to present a meaningful contribution to our knowledge and understanding of the representation of disability within museum collections, providing a vital snapshot of current best practice.

My research shows clear evidence for the importance of including disabled voices, enabling museums to improve their offerings to audiences and to draw on lived experience and expertise. Rather than advocating for simply handing over power, it appears that the most significant gains come when museum staff and disabled individuals work together from early in the project with expertise from both sides acknowledged, as in Dodd, Jones and Sandell's (2017) trading zones. Such collaboration allows links to be made and knowledge and understanding to be gained on both sides, rather than solely benefitting either participants or the museum.

The collaborative projects that these sites had undertaken had clear benefits for all those involved, and these benefits occurred even at points where the initial reasoning behind such work was the need to tick a box for funding. This is significant, as it suggests that carrying out these projects can have a meaningful result even if participants are not initially fully engaged with the process. This in turn provides hope that successful work can be carried out, and engagement developed, even if faced with initial reluctance from key staff. Such positive experiences will likely encourage the staff to continue with similar collaborative projects in their future work, both with disabled individuals and with other groups.

Furthermore, I have shown the increasing necessity for telling disabled stories within a wider scope of social activism for museums and explained the importance of emphasising the relevance of the stories being told. The stories that museums are sharing around disability are not only of interest to disabled lives – resonance can be drawn between these stories and other issues which affect society. Allowing these links to be explicit encourages meaningful engagement with the issues raised, and effectively challenges negative stereotypes which have been shown to be pervasive by emphasising the importance of disabled lives and achievements. It can also enable various marginalised and disadvantaged groups to see shared experiences, rather than leading to them regarding each other as rivals. Museums undertaking the work discussed here is particularly significant as museums are widely trusted (Ott, 2010, p. 270). By integrating disability stories within major galleries, they can ensure that these narratives are encountered even by individuals who would not necessarily seek them out intentionally. This enables them to challenge negative views, guiding rather than alienating their audiences.

Areas For Future Research

Having completed this thesis, a number of potential avenues for further research open up. These could not be pursued during this project as they were beyond the scope of my PhD, and yet they offer the possibility of valuable learning in the future.

First of all, I would be interested in exploring how disability stories could best be integrated within wider narratives, and in understanding the impact such work had on audiences. In particular, I wonder how audience members respond to the stories that they are faced with and in examining what meanings they draw out from this work. I am also curious to see how stories around disability can effectively be enfolded within more general stories that are being shared.

There is also the possibility of considering the effect that the coronavirus pandemic is having on the work of museums and how they are going about collaborating with groups – including the potential for wider collaboration that will be possible using

digital tools. Groups such as Vocaleyes (2020) highlight the importance of ongoing collaboration with disabled people, and the role of inclusive online events. They have emphasized the possibility for inclusivity which the pandemic has shown, and stress the importance of ensuring progress around accessibility and collaboration is not lost as sites reopen. With this in mind, I would be interested in discovering how disability can be included in sites which perhaps do not consider themselves to be activist and yet seek to appeal to a wide audience.

Due to the limited scope of my project, it was impossible to address questions of how audiences approached these exhibitions. However, learning how audiences perceive and make sense of the information presented would be of use in further evaluating the work being carried out, as would examining the impact that it had on various segments of the audience – for example disabled audience members, or those who are non-disabled and consider themselves uninterested in stories of disability.

Finally, I would be interested in seeing how museums can collaborate with disabled individuals on projects which are not solely focused on disability and examine society more holistically. I feel this would blend the two key discoveries of my work together well and lead to meaningful outcomes.

The ideas listed above are just a few of the avenues for future research that have been opened up as a result of my thesis and I am hopeful that in time I will be able to explore at least some of these paths, and also that others will be able to continue with my work.

Recommendations

Taking the contribution of this thesis into consideration, I have developed a few key recommendations, both theoretical and practical, which I will now explain, beginning with the theoretical implications of my work.

One of the key elements that I have uncovered is the importance of considering disability as a part of humanity and treating it as such. Stories of disability need to be both displayed separately and also integrated within the themes and key ideas of the

museum in order to fully engage with and examine these ideas, considering key questions about humanity and what it is to be human as well as giving a more truthful impression of the richness of life in past societies and across current cultures.

Related to this is the fact such displays cannot avoid engaging with politics to some extent. Museums are not neutral, and the social model of disability is in itself deeply political as it analyses the flaws in society which cause barriers to emerge. If museums seek to engage with this model in their display of disability, as I believe that they should, they will need to step beyond political neutrality, if only within a limited sphere. As part of this political turn, there is a necessity to include disabled voices in the work that is carried out.

Including the words and voices of disabled individuals in various ways is not only ethically important for the reasons discussed: it can also lead to a far clearer and more engaging exhibition for all visitors. Such concerns range from theory to issues around practical advice for museums. When working with disabled individuals, it is important to acknowledge both their expertise and your own, working alongside them and developing your own skills for collaborative work. It is also important that you approach the project with the goal of learning from each other and gaining a successful outcome that benefits both the museum and the participants.

When considering inclusion, it is important to do so widely. The space outside of the exhibition and the external marketing also need to be considered. In addition, for exhibitions to be truly inclusive, consideration must even be given to non-disabled individuals who need assistance to help them move beyond stereotypical concepts of disability towards deeper knowledge. One way of doing this is by drawing links between the disabled stories you are telling and wider narratives, rather than assuming this information will only be relevant to a small segment of your audience. By making these connections explicit, you can help your audience deepen their understanding, both of disability and of the themes that you seek to address.

This also requires an attempt at nuance and complexity. Many historic figures are linked to behaviours and practices that we find abhorrent today, and it is crucial to acknowledge this. Rather than displaying a disabled individual from history as flawless,

a far more interesting and engaging story can be told if they are considered first and foremost as a human – as flawed, complex and challenging as any one of us. This enables a better story to be told and ensures that what is shown is more truthful, increasing both audience interest and insight.

Final Remarks

This thesis has demonstrated the role that museums can play in ensuring that representations of disability are engaging and relevant to both disabled and non-disabled audience members. I have demonstrated the importance of considering how disabled voices can be amplified by the museum and how museums can work successfully in collaboration with disabled individuals. I also emphasised how disability is increasingly being considered as a part of the tapestry of humanity, with an explanation of how museums can work to represent this within their exhibitions and displays. This work is still ongoing, and may never be fully complete, but there have already been some fascinating exhibitions which make use of the social model. They do this in order to represent disabled individuals in a way that is more inclusive and can combat some of the negative stereotypes considered earlier in this thesis. It is important that such work continues, in order to ensure that such a large part of our shared story is no longer overlooked or forgotten.

I wish to conclude my thesis by giving a final thanks to all those involved who gave their time and energy to help me pursue this project, and most importantly to the disabled individuals past, present and future who are being represented now within museum spaces, as well as to those people whose stories remain lost.

Appendices

Appendix A – Semi-Structured Interview Questions

Key Questions:
How are disabled people and stories of disability currently represented in exhibitions and displays within UK museums? Which factors, aims and concerns shape these narratives?

Introduction:

This research aims to understand how museums represent disabled people and their stories, and to understand how decisions about their display come about. By interviewing those involved in the development of disability-focused exhibitions, the hope is that a deeper understanding can be gained.

Thank you very much for agreeing to talk to me. If we could start off with a couple of questions about your role within the museum?

Museum role:

- Please explain to me what your role is within the museum, and your previous roles?
- What work have you done previously involving hidden or minority histories?
- How did you become involved in this project?
- Which opportunities did this project offer which were different from your prior work?
  - Which opportunities were similar to work you had taken part in previously?

Thank you. Moving on to considering the exhibit in question, I would like to ask you about the planning and creation process.

Displaying disability:

- How did you feel about this topic when it was first proposed? Did this change?
- Why did you feel that this was a project that should be carried out?
- Why, in your opinion, did the museum decide to hold this exhibit now?
- How were the voices and views of disabled individuals used?
- Which messages did you want to leave the audience with? Why?
- Which challenges did you face in presenting disability-themed material?
  - How did you address these?
- Tell me about any of the opportunities this project offered.

Leaving behind the process of creating this exhibit, we now turn to reactions toward it.

Reactions:

- What was the response from the public, media, and stakeholder groups?
- How did you feel about the finished exhibition?
- If given the opportunity to do this exhibit again, what would you change?
- Which element of the exhibition are you most proud of?

Thank you. After discussing this exhibit, I just have a few final questions about the museum's future plans for the display and commemoration of disability.

Future Plans:

- What do you feel you have learned from this exhibit?
- Looking back on everything you have learned, what do you plan to take forwards?
- Please tell me about any future plans you are aware of which will include disability, in either permanent or temporary exhibitions.

Thank you. Do you have any questions, or anything you would like to know about my research?

Appendix B – Information Sheet and Consent Form

Information Sheet for Participants

Project Title: Displays of Difference: Representing Disability in Museums

Email Address: jh713@leicester.ac.uk

Date: 12th November 2018

I would like to tell you more about the nature of the project, and about who I am and why I am undertaking this research, as well as explaining how you were selected for the project. I would also like to inform you about how your data will be used and the protections of your privacy and confidentiality that are in place.

Who is doing the project?
I am Jenni Hunt, a PhD Student at the University of Leicester, working within the museums studies' department and examining how museums represent disability in their exhibitions and displays.

What is the project for?

To develop a better understanding of how disabled people and stories of disability are currently represented in exhibitions and displays within UK museums, and to see which factors shape these narratives.

How you were selected:

You were selected because of your role in the creation of an exhibition or display which focuses on the representation of disability and/or contains disability narratives.

Your role in completing the project:

You will be interviewed by me about your role in the creation of the exhibition/display and about the challenges you faced and choices you made when it came to the representation of disability. You will also be asked about past and future work in this area, and any co-curation or outreach which you did when working on this display.

Your rights:
Your participation in this research is entirely voluntary and you are free to withdraw from the project at any time before 1st September 2019. If you are uncertain or uncomfortable about any aspect of your participation please contact the researcher listed at the top of this letter to discuss your concerns or request clarification on any aspect of the study.

Protecting your confidentiality:

Any information you supply will be treated with respect and care. As the case studies I am examining will be named, it is likely that you will be identifiable. However, it is entirely your choice whether you are identified by name in the study. Data will be stored securely in accordance with GDPR 2016 and with the Data Protection Act 1988, with the information encrypted behind a password. Initially the interviews will be transcribed, and you have the opportunity to look at this transcription, before it is analysed for my research. I aim to make my thesis available to others, and to produce papers alongside my main thesis, based on the data gathered.

If you have any questions about the ethical conduct of the research please contact the Research Ethics Officer, Dr. Jen Walklate, on jaw72@leicester.ac.uk.

Thank you,

Jenni Hunt

Consent form

Project: Displays of Difference: Representing Disability in Museums

I agree to take part in the Displays of Difference study which is research towards a Museum Studies PhD at the University of Leicester.

I have had the research project explained to me and I have read the Information sheet about the project which I may keep for my records.

I understand that this study will be carried out in accordance with the University of Leicester's Code of Research Ethics which can be viewed at http://www2.le.ac.uk/institution/committees/research-ethics/code-of-practice, and with GDPR 2016 and the Data Protection Act 1988.

Material gathered as part of this study will be treated as confidential and securely stored.

I have read and I understand the information sheet	Yes ☐	No ☐
I have been given the opportunity to ask questions about the project and they were answered to my satisfaction	Yes ☐	No ☐
I understand that I can withdraw from the study at any time	Yes ☐	No ☐
I agree to the interview being recorded and my words being used for research purposes	Yes ☐	No ☐
I agree that my actual words can be used in any subsequent publications or use, including publication on the World Wide Web (Internet).	Yes ☐	No ☐

I give permission for the following personal details to be used in connection with any words I have said or information I have passed on:

My real name	Yes ☐	No ☐
The title of my position	Yes ☐	No ☐

My institutional affiliation	Yes ❑	No ❑

I request that my real name is acknowledged in any publications that references the comments that I have made	Yes ❑	No ❑

I understand anonymity is not guaranteed but that the study will comply at all times with the Data Protection Act (1988) and the recent GDPR (2016) meaning any data generated will be password protected and stored securely at the University of Leicester.	Yes ❑	No ❑

Name (PRINT) _____

Signed _____   Date _____

Please contact me if you have any questions or wish to withdraw from the research.

Jenni Hunt, PhD student, University of Leicester.

Email: jh713@leicester.ac.uk

Bibliography

Accentuate (2020) *Homepage* [online]
     Available at: http://www.accentuateuk.org/homepage (Accessed: 30 April 2020).

Accentuate (2021) *Curating for Change* [pdf] Accentuate. Available at:
     https://www.accentuateuk.org/domains/accentuate.org.uk/local/media/video/Curati
     ng_for_Change___Disabled_People_Leading_in_Museums.pdf (Accessed: 3
     March 2022).

ADA National Network (n.d.) *Guidelines for Writing About People with
     Disabilities*, ADA National Network. Available at:
     https://adata.org/factsheet/ADANN-writing (Accessed: 19 July 2021).

Adams, T. (2012, August) 'The Facebook Meme Fine Print under "Disability"', *Faith In
     Ambiguity,* Available at: http://faithinambiguity.blogspot.com/2012/08/the-
     facebook-meme-fine-print-under.html (Accessed: 9 October 2017).

Aguilera, R. (2000) 'Disability and Delight: Staring Back at the Devotee Community',
     Sexuality and Disability, 18(4), pp. 255-261.

Ali, N. and Callaghan, D. (2016) 'Community Engagement and Challenging the
     Authorised Narrative' In McSweeney, K. and Kavanagh, J. eds. *Museum
     Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 312-
     343.

Allday, K. (2009). 'From changeling to citizen: Learning disability and its
     representation in museums', *Museums and Society*, 7(1), pp. 32-49.

ALVA (2018) *Latest Visitor Figures* [online] Available at:
     http://www.alva.org.uk/details.cfm?p=423 (Accessed: 4 April 2018).

Antle, B. J, (2004) 'Factors Associated With Self Worth In Young People With Physical
     Disabilities', *Health & Social Work,* 29(3), pp. 167-175.

Are You Having a Laugh? TV and Disability (2010) [Television] BBC2: Mark Allen,
     Mark Murray.

Arnstein, S. R. (1969) 'A Ladder Of Citizen Participation', *Journal of the American
     Planning Association*, 35(4), pp. 216 – 224.

Arts Council England (2018) *Making a Shift Report* [online] Available at:
     http://www.artscouncil.org.uk/sites/default/files/download-
     file/ACE206%20MAKING%20A%20SHIFT%20Report%20FINAL.pdf
     (Accessed: 2 February 2018).

Arts Council England (2019) *Equality, Diversity and the Creative Case* [pdf] Available
     at: https://www.artscouncil.org.uk/sites/default/files/download-
     file/Diversity_report_1718.pdf (Accessed: 3 March 2022).

Arts Council England (2022) *Explore the strategy* [online] Available at:
    https://www.artscouncil.org.uk/strategy Accessed: 3 March 2022).

Avram, A. and Burcea, O. (2016) 'Planning for Participatory Exhibitions: Bringing
    Community Voices to the Forefront' In McSweeney, K. and Kavanagh, J. eds.
    Museum Participation: New Directions for Audience Collaboration, Museums Etc.,
    pp. 532-561.

Ayers, K. (2012) 'Desperation Porn', *Audacity Magazine.* Available
    at: http://www.audacitymagazine.com/desperation-porn-the-impact-of-graphic-
    medical-images-on-the-disability-community/ (Accessed: 9 October 2017).

Balter, R. (1999) 'From stigmatization to patronization: The media's distorted portrayal
    of physical disability' In L. L. Schwartz ed., *Psychology and the media, Vol. 2.
    Psychology and the media: A second look,* Washington, DC, US: American
    Psychological Association, pp. 147-171.

Barnes, C. (1992) *Disabled People in Britain and Discrimination: A Case for Anti-
    Discrimination Legislation.* London: Hurst and Co. pp. 1-17.

Barnes, C. and Mercer, G. (2003) *Disability,* First Edition. Cambridge: Polity Press. pp.
    88-109.

Barnes, C., Mercer, G. and Shakespeare, T. (1999) *Exploring Disability,* First Edition.
    Cambridge: Polity Press. pp.182-210.

Barounis, C. (2013) 'Crippling Heterosexuality, Queering Able-Bodiedness:
    Murderball, Brokeback Mountain and the Contested Masculine Body' In Davis,
    L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 381-397.

Basu, P. (2007) 'The Labrynthine Aesthetic in Contemporary Museum Design' In
    Macdonald, S. and Basu, P. eds. *Exhibition Experiments*, 1st ed. Wiley, pp. 25-46

BBC News (2017, October 12) 'Transcript: "I'm wearing a tight T-shirt so I know
    where I end", *BBC News,* Available at: http://www.bbc.co.uk/news/disability-
    41609693 (Accessed: 16 October 2017).

Ben-Moshe, L. (2013) '"The Institution Yet to Come": Analysing Incarceration through
    a Disability Lens' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge,
    pp. 132-143.

Berger, R. (2015) 'Now I see it, now I don't: researcher's position and reflexivity in
    qualitative research', *Qualitative Research*, 15(2), pp. 219-234.

Besley, J. and Low, C. (2010) 'Hurting and healing: reflections on representing
    experiences of mental illness in museums' In Sandell, R., Dodd, J., and Garland-
    Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 130-142.

Bethlem Museum of the Mind (2018) *About* [online] Available at: http://museumofthemind.org.uk/about (Accessed: 4 April 2018).

Biernoff, S. (2011) 'Medical archives and digital culture: from WWI to BioShock', *Medical history,* 55(3), pp. 325-330.

Binter, J.T.S. (2014) 'Unruly Voices in the Museum', *The Senses and Society*, 9(3), pp. 342-360.

Blyn, R. (2013) *The Freak-Garde: Extraordinary Bodies and Revolutionary Art in America,* First Edition U of Minnesota P.

Bogdan, R. (1990) *Freak Show,* Paperback First Edition. Chicago [u.a.]: Univ. of Chicago Press.

Bogdan, R., Elks, M. and Knoll, J.A. (2012) *Picturing Disability,* First Edition. Syracuse, N.Y: Syracuse Univ. Press.

Boylan, M. (2016) 'Agency and Disability; A rights based approach' In Gordon, J.S., Poder, J.C. and Burckhart, H. eds., *Human rights and Disability: Interdisciplinary Perspectives,* 1st ed. London: Routledge, pp. 154-170.

British Council (n.d.) *Unlimited* [online] Available at: https://www.britishcouncil.jp/en/programmes/arts/disability-arts/unlimited (Accessed: 20 August 2020).

British Museum (2018) *Desire, love, identity: LGBTQ histories trail* [online] Available at: https://www.britishmuseum.org/visit/object-trails/desire-love-identity-lgbtq-histories (Accessed: 22 June 2020).

Brown, C. (2018) 'Unboxing history exhibitions: experience design in museum practice' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds., *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 213-224.

Building Radical Accessible Communities (2012) 'Inspiration Porn', Available at: http://buildingradicalaccessiblecommunities.blogspot.com/2012/02/inspiration-porn.html (Accessed: 9 October 2017).

Bunnika (2012) 'Did You Know Cripples Can Do Things?: Inspiration Porn and the Ableist Commodification of Disabled Bodies', *bunnika's blog,* Available at: https://bunnika.wordpress.com/2012/12/15/did-you-know-cripples-can-do-things/ (Accessed: 9 October 2017).

Bunning, K., Kavanagh, J., McSweeney, K. and Sandell, R. (2015). *Embedding plurality: exploring participatory practice in the development of a new permanent gallery*. [online] Science Museum Journal. Available at: http://journal.sciencemuseum.ac.uk/browse/issue-03/embedding-plurality-exploring-participatory/ (Accessed: 6 March 2019).

Burch, L. (2017): '"You are a parasite on the productive classes": online disablist hate speech in austere times', *Disability & Society* 3(3), pp. 392-315.

Burckhart, H. and Jager, B. (2016) 'On Human rights and human duties: Is there a moral obligation to inclusion?' In Gordon, J.S., Poder, J.C. and Burckhart, H. eds., *Human rights and Disability: Interdisciplinary Perspectives,* 1ˢᵗ ed. London: Routledge, pp. 68-73.

Burns, S. and Haller, B. (2015) 'The Politics of Representing Disability: Exploring News Coverage of the Americans with Disabilities Act and the National Disability Insurance Scheme', *Asia Pacific Media Educator,* 25(2), pp. 262-277.

Cambridge English Dictionary (2011) *Cambridge English Dictionary*. Available at: https://dictionary.cambridge.org/dictionary/english/disability. (Accessed: 20 July 2021)

Cameron, C. (2015) *Why we are disabled people, not people with disabilities*, Disability Arts Online. Available at: https://www.disabilityartsonline.org.uk/why-we-are-disabled-people-not-people-with-disabilities (Accessed: 19 July 2021).

Carden-Coyne, A. (2010) 'Ghosts in the War Museum' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 64-78.

Chambers, E. (2010) 'Face to face: representing facial disfigurement in a museum context' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 179-194.

Chambers, M. (1999) 'Critiquing Exhibition Criticism inc. notes' *Museum News,* American Alliance of Museums, Sept/Oct, pp.31-37, 65.

Channel 4 (2012) *Research: Paralympics coverage helped change attitudes to disability.* Channel 4. Available at: http://www.channel4.com/info/press/news/research-paralympics-coverage-helped-change-attitudes-to-disability. (Accessed: 2 October 2017).

Channel 4 (2014) *'A long way to go' – Paralympian on attitudes to disability.* Channel 4. Available at: https://www.channel4.com/news/disability-paralympic-games-london-2012-attitudes-improved (Accessed: 2 October 2017).

Chemers, M. (2004) 'Mutatis Mutandis: An Emergent Disability Aesthetic in "X-2: X-Men United"', *Disability Studies Quarterly*, 24(1) http://dsq-sds.org/article/view/862/1037 (Accessed: 18 June 2021)

Chemers, M. (2005) 'Guest Editor's Introduction: Staging Stigma: A Freak Studies Manifesto', *Disability Studies Quarterly*, 25(3), https://dsq-sds.org/article/view/574/751 (Accessed: 19 September 2020).

Chen, C-L. (2010) 'Disability, human rights and the public gaze: The Losheng Story Museum' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 244-256.

Chimirri-Russell, G. (2010) 'The red wheelchair in the white snowdrift' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 168-178.

Church, D. (2006) 'From Freaks to Scissorhands: Fantastic Films, Fantastic Bodies: Speculations on the Fantastic and Disability Representation', *Offscreen,* 10(10). https://offscreen.com/view/fantastic_films_fantastic_bodies (Accessed: 19 September 2020).

Church, D. (2011) 'Freakery, Cult Films, and the Problem of Ambivalence', *Journal of Film and Video,* 63(1), pp. 3-17

Church, K., Panitch, M., Frazee, C. and Livingstone, P. (2010) '"Out from Under": a brief history of everything' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 197-212.

Cohen-Rottenberg, R. (2013) *Disability and Representation | Changing the Cultural Conversation* [online] Available at: http://www.disabilityandrepresentation.com/2013/01/ (Accessed: 9 October 2017).

Colonial Countryside (2018) *Colonial Countryside – Youth led History* [online] Available at: https://colonialcountryside.wordpress.com/ (Accessed: 22 June 2020).

Cooley, J. and Fox, A. M. (2014) 'Disability Art, Aesthetics, and Access: Creating Exhibitions in a Liberal Arts Setting', *Disability Studies Quarterly,* 34(1), https://dsq-sds.org/article/view/3288/3530 (Accessed: 19 September 2020).

Cowan, A. (2019, April 16), Personal Communication with Jenni Hunt [Personal Interview – In Person].

Cox, D. (2012, November 12) 'Disability in film: is cinema finally moving with the times?', *The Guardian*, Available at: http://www.theguardian.com/film/filmblog/2012/nov/12/disability-in-film-untouchable (Accessed: 15 October 2017).

Creswell, J.W. (2003) *Research Design,* Second Edition. Thousand Oaks, Calif: Sage Publications.

Dark, S. (1922) *The life of Sir Arthur Pearson, newspaper proprietor and founder of St. Dunstan's hostel for sailors and soldiers blinded in the great war, 1914-1918*, (P. 140) Hodder and Stoughton, London [online] https://archive.org/stream/lifeofsirarthurp00darkuoft#page/140/mode/1up (Accessed: 20 February 2021).

Delin, A. (2002) 'Buried in the footnotes: the absence of disabled people in the collective imagery of our past' In Sandell, R. ed. *Museums, Society, Inequality*, 1st ed. Routledge, pp. 84-97

Denscombe, M. (2007) *The Good Research Guide for Small Scale Social Research Projects,* Third Edition. Maidenhead [u.a.]: Open Univ. Press.

DePoy, E and Gilson, S. (2013) 'Disability, Design and Branding: Rethinking Disability for the 21st Century' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 485-496.

Disability Thinking (2013) *The Sick Children Meme*, Disability Thinking. Available at: http://disabilitythinking.blogspot.com/2013/11/the-sick-children-meme.html (Accessed: 9 October 2017).

Disability Unit, Cabinet Office. (2021) *Inclusive Language: words to use and avoid when writing about disability*, Gov.UK, Available at: https://www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability (Accessed: 19 July 2021).

Dodd and Jones. (2014). *Mind, body, spirit: How museums impact health and wellbeing,* [pdf] Leicester, RCMG. Available at: https://le.ac.uk/rcmg/publications (Accessed: 20 August 2021).

Dodd, J., Hooper-Greenhill, E., Delin, A. and Jones, C. (2006). *In the Past we Would Just Be Invisible: Research into the disabled people to museums and heritage for Colchester Museums* [pdf] Leicester, RCMG. Available at http://www2.le.ac.uk/departments/museumstudies/rcmg/projects/colchester-museums (Accessed: 14 November 2017).

Dodd, J., Jones, C., Jolly, D. and Sandell, R. (2010) 'Disability reframed: Challenging Visitor Perceptions in the Museum' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 92-111.

Dodd, J., Jones, C. and Sandell, R. (2017), 'Trading Zones: Collaborative Ventures in Disability History' In Gardner, J. and Hamilton, P. eds., *Handbook of Public History, 1st ed.* Oxford: Oxford University Press, pp. 87-104.

Dodd, J., Sandell, R., Delin, A. and Gay, J. (2004) *Buried in the Footnotes: The representation of disabled people in museum and gallery collections* [pdf] Leicester, RCMG Available at http://hdl.handle.net/2381/33 (Accessed: 1 April 2018).

Dowell, B. (2009, February 28) 'TV presenter's calm take on prejudice', *The Guardian,* Available at: http://www.theguardian.com/society/2009/feb/28/disability-cerrie-brunell-bbc (Accessed: 2 October 2017).

Dubin, S. (1999) *Displays of Power: Controversy in the American Museum from the Enola Gay to Sensation,* First Edition. New York, New York University Press.

Duncan, T. and McCauley, N. (2012) 'A narrative journey: creating storytelling environments with architecture and digital media' In MacLeod, S., Hourston Hanks, L. and Hale, J. eds. *Museum making*, London: Routledge, pp. 288-297.

Easton, G. (2010) 'Critical realism in case study research', *Industrial Marketing Management,* 39(1), pp. 118-128.

Eisenhauer, J. (2007) 'Just Looking and Staring Back: Challenging Ableism through Disability Performance Art', *Studies in Art Education,* 49(1), pp. 7-22.

Ellis, K. (2003) 'Reinforcing the Stigma - the Representation of Disability in Gattaca', *Australian Screen Education Online,* (31), pp. 111-114.

Ellis, K. (2015) *Disability and Popular Culture,* First Edition. Farnham [u.a.]: Ashgate.

Ellis, L. (2017) 'Through a filtered lens: unauthorized picture-taking of people with dwarfism in public spaces', *Disability & Society,* 33(2), pp. 218-237.

Emmens, S. (2018, November 14), Personal Communication with Jenni Hunt [Personal Interview – In Person].

Emmens, S. (2020) *Wounded: An Exhibition Out of Time* [online] Available at: http://journal.sciencemuseum.ac.uk/browse/issue-13/wounded/ (Accessed: 9 July 2020).

Erevelles, N. (2014) '"Becoming Disabled": Towards the Political Anatomy of the Body' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds. *Disability, Human Rights and the Limits of Humanitarianism.* 1st ed. GB: Routledge Ltd. 99, pp. 219-234.

Evans, D. (2013) *Cara's Post Goes Viral…More Disability Discussion on the Alcohol Meme,* DominickEvans.com. Available at: http://www.dominickevans.com/2013/12/caras-post-goes-viral-more-disability-discussion-on-the-alcohol-meme/ (Accessed: 9 October 2017).

Farnall, O. and Smith, K.A. (1999) 'Reactions to People with Disabilities: Personal Contact versus Viewing of Specific Media Portrayals', *Journalism & Mass Communication Quarterly,* 76(4), pp. 659-672.

Fiedler, L.A. (1993) *Freaks: Myths and Images of the Secret Self,* First Edition. United States: Anchor Books.

Filene, B. (2017), 'History Museums and Identity: Finding "Them", "Me" and "Us" in the Gallery' In Gardner, J. and Hamilton, P. eds., *Handbook of Public History, 1st ed.* Oxford: Oxford University Press, pp. 327-348.

Fox, E. (2018a, August 15), Personal Communication with Jenni Hunt [Personal Interview – Online].

Fox, E. (2018b, August 21), Personal Communication with Jenni Hunt [Personal Interview – Online].

Fraser, N. and Honneth, A. (2003) *Redistribution or Recognition?* First Edition. London [u.a.]: Verso.

Galison, P. (1997) *Image and Logic: A Material culture of Microphysics*, First Edition. Chicago, University of Chicago Press.

Garland-Thomson, R. (1996) *Freakery: Cultural Spectacles of the Extraordinary Body,* First Edition New York [u.a.]: New York Univ. Press

Garland-Thomson, R. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature,* First Edition. Columbia UP.

Garland-Thomson, R. (2000a) 'Staring Back: Self-Representations of Disabled Performance Artists', *American Quarterly,* 52(2), pp. 334-338.

Garland-Thomson, R. (2000b) 'Seeing the Disabled: Visual Rhetorics of Popular Disability Photography' In Longmore, P. and Umansky, L. eds., *The New Disability History American Perspectives*, 1st ed. New York University Press, pp. 335-74.

Garland-Thomson, R. (2006) 'Ways of Staring', *Journal of Visual Culture,* 5(2), pp. 173-192.

Garland-Thomson, R. (2009) *Staring,* First Edition. Oxford [u.a.]: Oxford Univ. Press.

Garland-Thomson, R. (2010) 'Picturing people with disabilities: Classical portraiture as reconstructive narrative' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 23-40.

Gartner, A. and Joe, T. (1987) *Images of the Disabled, Disabling Images,* First Edition. New York u.a: Praeger.

Gill, M and Schlund-Vials, C. (2014) 'Protesting "The Hardest Hit": Disability Activism and the Limits of Human Rights and Humanitarianism' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds. *Disability, Human Rights and the Limits of Humanitarianism.* 1st ed. GB: Routledge Ltd. 99, pp. 1-14.

Goggins, S., Phillipson, T. and Alberti, Samuel J M M (2017) 'Prosthetic limbs on display', *Science Museum Group Journal,* 8(08), http://dx.doi.org/10.15180/170806 (Accessed: 11 January 2019)

Govier, L. (2010) *Leaders in co-creation? Why and how museums could develop their co-creative practice with the public, building on ideas from the performing arts and other non-museum organisations*, RCMG Leicester. Available at: https://www2.le.ac.uk/departments/museumstudies/rcmg/projects/leaders-in-co-

creation/Louise%20Govier%20-%20Clore%20Research%20-
%20Leaders%20in%20Co-Creation.pdf (Accessed: 4 April 2019).

Graham, H. (2016) 'Museums Are Not Representative (And This is a Good Thing for Participation)' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 252-261.

Gro Gundersen, M and Back, C. (2018) 'Spatial meaning-making: exhibition design and embodied experience' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds. *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 304-316.

Grono, J. (2016) *How 'Finding Dory' Teaches Us to Stop Apologizing for Our Disabilities,* The Mighty. Available at: http://themighty.com/2016/06/how-finding-dory-shows-a-positive-representation-of-disability/ (Accessed: 10 October 2017).

Hadley, B. (2016) 'Cheats, charity cases and inspirations: disrupting the circulation of disability-based memes online', *Disability & Society,* 31(5), pp. 676-692.

Hale, J. (2012) 'Narrative environments and the paradigm of embodiment' In MacLeod, S., Hourston Hanks, L. and Hale, J. eds. *Museum making*, London: Routledge, pp. 192-200.

Hale, J. and Back, C. (2018) 'From body to body: architecture, movement and meaning in the museum' experience' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds. *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 340-351.

Haley, B. and Wilson, O. (2018) 'New approaches to universal design at The Gateway Arch National Park' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds. *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 175-188.

Hall, S. (1997) *Representation: Cultural Representations and Signifying Practices,* Second Edition. London: Sage.

Hartman, C. (2012, July 27) 'Is It Offensive to People with Disabilities When People Post Inspiring Pictures of People with Disabilities?', *Huffington Post,* Available at: https://www.huffingtonpost.com/quora/is-it-offensive-to-people_b_1708074.html (Accessed: 9 October 2017).

Helm, T. (2018, April 14) 'Disabled people lose legal aid in 99% of benefits disputes', The Guardian, Available at: https://www.theguardian.com/society/2018/apr/14/disabled-people-lose-legal-aid-99-per-cent-benefits-disputes (Accessed: 11 January 2022).

Heritage Lottery Fund (n.d.a) *Outcomes*. Available at: https://www.heritagefund.org.uk/funding/outcomes (Accessed: 7 March 2019).

Heritage Lottery Fund (n.d.b) *Outcomes – the detail*. Available at: https://www.heritagefund.org.uk/publications/outcomes-detail (Accessed: 7 March 2019).

Hevey, D. (2010a) 'Behind the shadow of Merrick' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 79-91.

Hevey, D. (2010b) 'Behind the shadow of Merrick' [video] Available at: http://www.showmetheaccess.co.uk/education/museums_and_galleries/Behind_the_Shadow_of_Merrick/ (Accessed: 19 August 2021).

Hevey, D. (2013) 'The Enfreakment of Photography' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 432-446.

Hevey, D. (2018, December 9), Personal Communication with Jenni Hunt [Personal Interview – In Person].

Hickling, A. (2017a, May 8) 'Mat Fraser on playing Richard III: 'I'd begun to feel like yesterday's cripple'', *The Guardian,* Available at: http://www.theguardian.com/stage/2017/may/08/mat-fraser-interview-richard-iii-disability-northern-broadsides (Accessed: 3 October 2017).

Hickling, A. (2017b, May 11) 'Richard III review – Mat Fraser proves a brilliant villain for Northern Broadsides', *The Guardian,* Available at: http://www.theguardian.com/stage/2017/may/11/richard-iii-hull-truck-theatre-review-mat-fraser-northern-broadsides (Accessed: 3 October 2017).

History of Place (2019) *A Quick Guide to the History of Place Project* [online] Available at: https://historyof.place/a-quick-guide-to-the-history-of-place-project/ (Accessed: 25 February 2022).

Hitt, A. (2013) *#cwcon 2013*. Accessing Rhetoric. Available at: https://allisonhitt.wordpress.com/2013/06/07/cwcon-2013/ (Accessed: 9 October 2017).

Hollins, H. (2010) 'Reciprocity, accountability, empowerment: emancipatory principles and practices in the museum' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 228-243.

Holton, A.E., Farrell, L.C. and Fudge, J.L. (2014) 'A Threatening Space?: Stigmatization and the Framing of Autism in the News', *Communication Studies,* 65(2), pp. 189-207.

Hourston Hanks, L. (2012) 'Writing spatial stories: Textual narratives in the museum' In MacLeod, S., Hourston Hanks, L. and Hale, J. eds. *Museum making*, London: Routledge, pp. 21-33.

Imperial War Museums (2018a) *First World War Galleries* [online] Available at: https://www.iwm.org.uk/events/first-world-war-galleries (Accessed: 4 April 2018).

Imperial War Museums (2018b) *IWM London* [online] Available at: https://www.iwm.org.uk/visits/iwm-london (Accessed: 9 April 2018).

"Into the Ring" Daredevil. (2015). [Online Streaming.] Netflix: Phil Abraham.

Iyer, A. (2007) 'Depiction of intellectual disability in fiction,' *Advances in Psychiatric Treatment,* 13(2), pp. 127-133.

Janzen R, (2012) 'Review: Haller, Beth A. Representing Disability in an Ableist World: Essays on Mass Media', *Canadian Journal of Disability Studies*, 1(2), pp. 109-111.

John Ellerman Foundation (n.d.) *Apply for funding – Museums and Galleries Fund* [online] Available at: https://ellerman.org.uk/apply-for-funding/museums-and-galleries-fund (Accessed: 3 March 2022).

Joined: The Secret Lives of Siamese Twins (2002) [Film] Real Stories: Mark Galloway.

Jones, K. (2018, October 2), Personal Communication with Jenni Hunt [Personal Interview – In Person].

Kanake, S. (2016) *Friday essay: on telling the stories of characters with Down syndrome.* The Conversation. Available at: http://theconversation.com/friday-essay-on-telling-the-stories-of-characters-with-down-syndrome-56436 (Accessed: 29 September 2017).

Kim, E. (2014) 'The Specter of Vulnerability and Disabled Bodies in Protest' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds. *Disability, Human Rights and the Limits of Humanitarianism.* 1st ed. GB: Routledge Ltd. 99, pp. 137-154.

Kingston, C. (2018, December 5), Personal Communication with Jenni Hunt [Personal Interview – In Person].

Kitchin, R. (2000) 'The Researched Opinions on Research: Disabled People and Disability Research', *Disability & Society,* 15(1), pp. 25–47.

Kiteley, P. and Robinson, B. (2017, October 15) 'Disabled children hate crimes reports increasing', *BBC News,* Available at: http://www.bbc.co.uk/news/uk-41600137 (Accessed: 15 October 2017).

Kleege, G. (2013) 'Blindness and Visual Culture: An Eyewitness Account' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 447-455.

Kudlick, C.J. (2003) 'Why We Need Another "Other"', *The American Historical Review,* 108(3) pp. 763-793.

Lehrer, R. (n.d.) *The Risk Pictures*. RivaLehrerArt Available at: https://www.rivalehrerart.com/risk-pictures (Accessed: Nov 23, 2017).

Lennon, R.. (2018) 'Forever, for everyone?' In Sandell, R., Lennon, R. and Smith, M. eds. *Prejudice and Pride: LGBTQ heritage and its contemporary implications,* RCMG/National Trust, pp. 10-17.

Levitt, A. (2013) *The art of disability on display at Bodies of Work* [online] Available at: https://www.chicagoreader.com/chicago/bodies-of-work-festival-disability-arts-culture/Content?oid=9562482 (Accessed: 6 December 2017).

Lewis, B. (2013) 'A Mad Fight: Psychiatry and Disability Activism' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 115-132.

Liverpool Museums (2018a) *Mission, values and strategic plan, Liverpool museums* [online] Available at: http://www.liverpoolmuseums.org.uk/about/corporate/strategic-plan/ (Accessed: 4 April 2018).

Liverpool Museums (2018b) *The Blind School Exhibition - Pioneering People and Places* [online] Available at: http://www.liverpoolmuseums.org.uk/mol/exhibitions/blind-school/ (Accessed: 4 April 2018).

Liverpool Museums (2019) *About the Museum of Liverpool* [online] Available at: https://www.liverpoolmuseums.org.uk/mol/about/ (Accessed: 25 October 2019).

Liverpool Museums (2020) *Strategic Plan* [online] Available at: https://www.liverpoolmuseums.org.uk/national-museums-liverpool-strategic-plan (Accessed: 25 May 2020).

Longmore, P. (2004) *Why I Burned My Book, and Other Essays on Disability,* First Edition. Temple University Press, Philadelphia.

Lopez, K. (2017, October 13) 'Why is Hollywood Following the Same Disabled Narrative?', *The Mary Sue,* Available at: https://www.themarysue.com/disabled-movie-narratives/ (Accessed: 15 October 2017).

Lord, J.E. (2014) 'Persons with Disabilities in International Humanitarian Law – Paternalism, Protectionism or Rights' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds. *Disability, Human Rights and the Limits of Humanitarianism.* 1st ed. GB: Routledge Ltd. 99, pp.155-178.

Macdonald, S. (2001) 'Ethnography in the Science Museum' In Gellner, D. N. and Hirsch, E. eds. *Inside Organizations: Anthropologists at Work*, Oxford and New York: Berg, pp. 77–96.

MacLeod, S. (2018) 'An ethical future for museum and gallery design: design as a force for good in a diverse cultural sector' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds. *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 13-28.

MacLeod, S., Hale, J., Austin, T. and Ho, O. (2018) 'Top 20 Principles for the future of museum and gallery design' In MacLeod, S., Hale, J., Austin, T. and Ho, O. eds. *The Future of Museum and Gallery Design*, 1st ed. London: Routledge, pp. 352-353.

Majewski, J. and Bunch, L. (1998) 'The Expanding Definition of Diversity: Accessibility And Disability Culture Issues in Museum Exhibitions', *Curator: The Museum Journal,* 41(3), pp. 153-160.

Marstine, J. (2011), 'The contingent nature of the new museum ethics', in Marstine, J. ed., *The Routledge Companion to Museum Ethics,* Routledge: Routledge Oxon, pp. 3-25.

Marvel Wikia (n.d.) *Clinton Barton (Earth-616).* Marvel Wikia. Available at: http://marvel.wikia.com/wiki/Clinton_Barton_(Earth-616)(Accessed: 10 October 2017).

Mason, J. (2018) *Qualitative Researching*, Third edition. Los Angeles: SAGE.

Mathur, S. (2000) 'Living Ethnological Exhibits: The Case of 1886', *Cultural Anthropology*, 15(4), pp. 492-524.

McEnroe, N. (2018, November 14), Personal Communication with Jenni Hunt [Personal Interview – In Person].

McRuer, R. (2012) 'Enfreakment; or, Aliens of Extraordinary Disability' in Dingo, R. and Scott, J. eds., *The Megarhetorics of Global Development*, 1st ed. University of Pittsburgh Press, pp. 233-252.

McSweeney, K. and Kavanagh, J. (2016) 'Introduction: Museum Participation' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 14-25.

Millett-Gallant, A. (2013) 'Sculpting Body Ideals: Alison Lapper Pregnant and the Public Display of Disability' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 398-410.

Mitchell, D., and Snyder, S.L. (2000) *Narrative Prosthesis,* First Edition. Ann Arbor, Mich: Univ. of Michigan Press.

Mitchell, D., and Snyder, S. (2013) 'Narrative Prosthesis' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 222-235.

Mortimer, C. (2015, November 8) 'Hate crime against disabled people rises 41 per cent in one year', *Independent,* Available at: http://www.independent.co.uk/news/uk/hate-crime-against-disabled-people-rises-41-per-cent-in-one-year-a6713546.html (Accessed: 5 October 2017).

Mortimer, N. (2017) *Maltesers' ads featuring disabled actors prove to be 'most successful' advert for the brand in 10 years.* The Drum. Available at: http://www.thedrum.com/news/2017/04/05/maltesers-ads-featuring-disabled-actors-prove-be-most-successful-advert-the-brand-10 (Accessed: 10 October 2017).

Mottram, J. (2007, January 10) 'If I Ate Out Of A Dog Bowl, Would You Like Me More', *Submit* Response, Available at: http://submitresponse.co.uk/weblog/2007/01/10/if-i-ate-out-of-a-dog-bowl-would-you-like-me-more/ (Accessed: 9 October 2017).

Nario-Redmond, M.R. (2010) 'Cultural stereotypes of disabled and non-disabled men and women: consensus for global category representations and diagnostic domains', *The British Journal of Social Psychology,* 49(3), pp. 471-488.

National Army Museum (2019a) *About the Museum* [online] Available at: https://www.nam.ac.uk/about/about-the-museum (Accessed: 18 October 2019).

National Army Museum (2019b) *Galleries* [online] Available at: https://www.nam.ac.uk/plan-visit/galleries (Accessed: 18 October 2019).

National Trust (2010) *Spectrum of Participation* [Internal Document].

NDACA (2018) *About NDACA* [online] Available at: http://www.ndaca.org.uk/about-ndaca (Accessed: 2 April 2018).

NDACA (2019a) *NDACA* [online] Available at: https://the-ndaca.org/ (Accessed: 28 October 2019).

NDACA (2019b) *The NDACA Wing* [online] Available at: https://the-ndaca.org/resources/the-ndaca-learning-centre/ (Accessed: 28 October 2019).

NDACA (n.d.) Exhibition panel, visited 16 April 2019.

O'Donnell, C. (2016) 'Play Your Part: From Audiences to Activists' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 392-409.

Oliver, M. (1992) 'Changing the Social Relations of Research Production?' *Disability, Handicap and Society,* 7(4), pp. 101-114.

Oliver, M. (2010) *Understanding Disability,* Second Edition. Basingstoke [u.a.]: Palgrave MacMillan.

O'Neill, B. (2007, May 17) 'Statue of limitations', *The Guardian,* Available at: http://www.theguardian.com/commentisfree/2007/may/17/statueoflimitations (Accessed: 2 October 2017).

Ott, K. (2005) 'Disability and the Practice of Public History: An Introduction', *The Public Historian,* 27(2), pp. 9-24.

Ott, K. (2010) 'Collective bodies: what museums do for disability' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 269-279.

Ouellete, A. (2016) 'General Introduction' In Gordon, J.S., Poder, J.C. and Burckhart, H. eds., *Human rights and Disability: Interdisciplinary Perspectives,* 1st ed. London: Routledge, pp. 1-6.

Our_Objects (2020) *Our Objects* [online] Available at: https://twitter.com/our_objects (Accessed: 31 January 2020).

Pepper, P. (2016, October 31) 'Maltesers' ads with disabled actors make me feel queasy. But at least they're trying', *The Guardian,* Available at: http://www.theguardian.com/commentisfree/2016/oct/31/maltesers-advertisments-disability-disabled-actors (Accessed: 10 October 2017).

Pepper, P. (2018, January 31) 'Disabled actors on prime-time TV? No wonder I cried at Silent Witness', *The Guardian*. Available at: https://www.theguardian.com/commentisfree/2018/jan/31/disabled-actors-prime-time-tv-silent-witness-mainstream-drama-abusive-political-climate (Accessed: 19 April, 2018).

Phiri, V. (2010) 'See no evil' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 53-63.

Piehl, J. and MacLeod, S.. (2012) 'Where do you want the label? The roles and possibilities of exhibition graphics' In MacLeod, S., Hourston Hanks, L. and Hale, J. eds. *Museum making*, London: Routledge, pp. 257-266.

Pioneering People and Places, Museum of Liverpool (n.d.) Exhibition panel, visited 09 March 2018.

Porto, N. (2007) 'From Exhibiting to Installing Ethnography: Experiments at the Museum of Anthropology of the University of Coimbra (Portugal) 1999-2005' In Macdonald, S. and Basu, P. eds. *Exhibition Experiments*, 1st ed. Wiley, pp. 175-196

Purce, E. (2017) 'Scales of Normality: Displays of Extreme Weight and Weight Loss in Blackpool 1920–1940', *Cultural and Social History*, 14(5), pp. 669-689.

Quayson, A. (2013) 'Aesthetic Nervousness' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 202-213.

Rainbow Jews (2013) *Rainbow Jews* [online] Available at: http://www.rainbowjews.com/ (Accessed: 22 June 2020).

Randjelovic, N., Pirsl, D. and Pirsl, T. (2012) 'Issues on Disability Advertising Imaging in Media', *Sport Mont Journal,* X(34-35-36), pp. 536-541.

Reinhardt, J.D., Pennycott, A. and Fellinghauer, B.A.G. (2014) 'Impact of a film portrayal of a police officer with spinal cord injury on attitudes towards disability: a media effects experiment', *Disability and Rehabilitation,* 36(4), pp. 289-294.

Renwick, R., Schormans, A.F. and Shore, D. (2014) 'Hollywood Takes on Intellectual/Developmental Disability: Cinematic Representations of Occupational Participation', *OTJR: Occupation, Participation and Health,* 34(1), pp. 20-31.

Research Centre for Museums and Galleries (2019) *Cabinet of Curiosities, how Disability was kept in a Box.* [online] Available at: https://le.ac.uk/rcmg/research-archive/cabinet-of-curiosities (Accessed: 25 October 2019).

Research Centre for Museums and Galleries (2020) *Disorder, dissent and disruption* [online] Available at: https://le.ac.uk/rcmg/research-archive/disorder-dissent-disruption (Accessed: 20 February 2021).

Riddle, A. (2016) 'Grounding Disability and Human Rights with the Capabilities approach' In Gordon, J.S., Poder, J.C. and Burckhart, H. eds., *Human rights and Disability: Interdisciplinary Perspectives,* 1st ed. London: Routledge, pp. 39-49.

Riley, C.A. (2005) *Disability and the Media,* First Edition. Hanover, NH: Univ. Press of New England.

Riley Smith, B. (2012, June 19) 'Hate crimes against disabled people soar to a record level', *Independent*, Available at: http://www.independent.co.uk/news/uk/crime/hate-crimes-against-disabled-people-soar-to-a-record-level-7858841.html (Accessed: 7 December 2017).

Royal Museums Greenwich (2018a) *Explore the Nelson, Navy, Nation gallery* [online] Available at: https://www.rmg.co.uk/see-do/we-recommend/attractions/nelson-navy-nation-gallery (Accessed: 4 April 2018).

Royal Museums Greenwich (2018b) *Who was Nelson?* [online] Available at: https://www.rmg.co.uk/stories/topics/nelson-man (Accessed: 20 August 2021).

Rule, P. and John, V.M. (2015) 'A Necessary Dialogue', *International Journal of Qualitative Methods,* 14(4), pp. 1-11.

Samuels, E. (2013) 'My Body, My Closet: Invisible Disability and the Limits of Coming Out' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 316-332.

Sandell, R. (2005) 'Constructing and communicating equality: the social agency of museum space' In MacLeod, S. ed., *Reshaping Museum Space: architecture, design, exhibitions*, Routledge: London, pp.185-200.

Sandell, R. (2007) *Museums, Prejudice and the Reframing of Difference,* First Edition. London [u.a.]: Routledge.

Sandell, R. (2011), 'On ethics, activism and human rights", in Marstine, J. ed., *The Routledge Companion to Museum Ethics,* Routledge: Routledge Oxon, pp. 129-145.

Sandell, R. (2019) 'Disability: Museums and our understanding of difference' In Knell, S. ed., *The Contemporary Museum: shaping museums for the global now,* 1st ed. London and New York: Routledge, pp. 169-184.

Sandell, R and Dodd, J. (2010) 'Activist Practice' In Sandell, R., Dodd, J., and Garland-Thomson, R. eds., *Re-Presenting Disability*, 1st ed. Oxon: Routledge, pp. 3-22.

Sandell, R. and Fraser, M. (2014, February 20). 'Outside the box: rethinking how museums present disability', *The Guardian,* Available at: http://www.theguardian.com/culture-professionals-network/culture-professionals-blog/2014/feb/20/outside-box-rethinking-museums-disability (Accessed: 28 September 2017).

Sandell, R., McSweeney, K. and Kavanagh, J. (2016) 'A Reflection on Participation' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 578-600.

Saxton, M. (2013) 'Disability Rights and Selective Abortion' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 87-99.

Science Museum (2018a) *Wounded: Conflict, Casualties and Care | Science Museum* [online] Available at: https://www.sciencemuseum.org.uk/see-and-do/wounded-conflict-casualties-and-care (Accessed: 4 April 2018).

Science Museum (2018b) *Wounded Symposium* [online] Available at: https://www.sciencemuseum.org.uk/researchers/wounded-symposium (Accessed: 18 October 2018).

Science Museum. (2018c) *Wounded: Conflict, Casualties and Care | Science Museum* [online] Available at: https://www.sciencemuseum.org.uk/what-was-on/wounded-conflict-casualties-and-care (Accessed: 7 April 2020).

Science Museum (2019) *About Us* [online] Available at: https://www.sciencemuseum.org.uk/about-us (Accessed: 25 October 2019).

Science Museum (2020a) *Medicine: The Wellcome Galleries Conference* [online] Available at: https://www.sciencemuseum.org.uk/see-and-do/medicine-wellcome-galleries-conference (Accessed: 31 January 2020).

Science Museum (2020b) *Portrait Series for the Medicine Galleries* [online] Available at: https://www.sciencemuseumgroup.org.uk/blog/medicine-galleries-sian-davey/ (Accessed: 28 April 2021).

Scully, J.L. (2008) *Disability Bioethics,* First Edition. Lanham [u.a.]: Rowman & Littlefield, pp. 107-131.

Seidler, C.O. (2011) 'Fighting Disability Stereotypes with Comics: "I Cannot See You, But I Know You Are Staring at Me"', *Art Education,* 64(6), pp. 20-23.

Serrell, B. (2006) *Judging Exhibitions: A Framework for Assessing Excellence*, Fist Edition. Left Coast Press.

Shakespeare, T. (1996) 'Disability, identity and difference' In Barnes C. and Mercer, G. eds., *Exploring the Divide*, Leeds: The Disability press, pp. 94-113.

Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited,* Second Edition. London [u.a.]: Routledge.

Shakespeare, W. and Cartelli, T. (2009) *Richard III.* First Edition. New York [u.a.]: Norton.

Shape Arts (2019) *Tony Heaton, OBE* [online] Available at: https://www.shapearts.org.uk/faqs/staff (Accessed: 10 January 2020).

Shape Arts (2020) *Breaking the barriers to creative excellence* [online] Available at: https://www.shapearts.org.uk/about-shape (Accessed: 25 May 2020).

Shtromberg, E. (2012) '*Enchanted Carcass* (1972): Sensory Overload and the Institutional Challenge of Decaying Art', *Third Text* 26(6), pp. 665-674.

Siebers, T. (2002) 'Broken Beauty: Disability and Art Vandalism', *Michigan Quarterly Review,* XLI(2), http://hdl.handle.net/2027/spo.act2080.0041.206. (Accessed: June 10 2020).

Silvers, A. and Pickering Francis, L. (2016) 'Human and Civil models of rights: Healthy and ill disabled and access to health care' In Gordon, J.S., Poder, J.C. and Burckhart, H. eds., *Human rights and Disability: Interdisciplinary Perspectives,* 1st ed. London: Routledge, pp. 132-153.

Simon, N. (2010) *The Participatory Museum, Museum 2.0* [online] Available at: http://www.participatorymuseum.org/ (Accessed: 7 March 2019).

Skolnick, L. (2012) 'Beyond Narrative: designing epiphanies' In MacLeod, S., Hourston Hanks, L. and Hale, J. eds. *Museum making*, London: Routledge, pp. 83-94.

Smith, H., Ginley, B., and Goodwin, H. (2012) 'Beyond Compliance? Museums, Disability and the Law' In. Sandell R. and Nightingale E. eds., *Museums, Equality and Social Justice*, 1st ed. London Routledge, pp. 59-71.

Smith Kogan, N. (2016) 'Aberrations in the Body and in the Body Politic: The Eighteenth-Century Life of Benjamin Lay, Disabled Abolitionist' *Disability Studies Quarterly* 36(3) Available at: https://dsq-sds.org/article/view/5135/4410 (Accessed: June 10 2020).

Smith, T-A. and Fouseki, K. (2016) 'Participatory Practices in Museums: A Seismic Shift' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 472-491.

Smithsonian (2013) *EveryBody: An Artifact History of Disability in America* [online] Available at: https://everybody.si.edu/ (Accessed: 6 December 2017).

Snyder, S.L. and Mitchell, D.T. (2006) *Cultural Locations of Disability,* First Edition. Chicago [u.a.]: Univ. of Chicago Press.

Soorenian, A. (2014) 'Media, Disability and Human Rights' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds., *Disability, Human Rights and the Limits of Humanitarianism,* 2nd ed. GB: Routledge, pp. 68-88.

Special Olympics (2005) *Changing Attitudes, Changing the World Media's Portrayal of People with Intellectual Disabilities* [pdf] Available at: http://www.specialolympics.org/uploadedFiles/LandingPage/WhatWeDo/Research _Studies_Desciption_Pages/Policy_paper_media_portrayal.pdf (Accessed: 3 October 2017).

Steven, R. (2016) *Rio Paralympics and Channel 4: telling a new story about disability.* Creative Review. Available at: https://www.creativereview.co.uk/i-hope-this-ad-will-be-an-important-step-forward-channel-4s-dan-brooke-on-the-new-superhumans-spot/ (Accessed: 2 October 2017).

Streets, K. (2016) 'It's About Us: Why It's Important to Keep in Touch' In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 132-135.

Sweney, M. (2014, March 5) 'Paddy Power's Oscar Pistorious ad to be pulled after record 5,200 complaints', *The Guardian,* Available at: https://www.theguardian.com/media/2014/mar/05/paddy-power-oscar-pistorius-ad-withdrawn-immediate-effect (Accessed: 1 November 2017)

Taylor, C. (1992) *Muliticulturalism and the Politics of Recognition,* First Edition. Princeton University Press pp. 25-73.

Telfer, B, Heaton T. and Anderson, J. (2011) *Re-framing disability: portraits from the Royal College of Physicians,* First Edition. London: Royal College of Physicians.

The Leicester Hate Crime Project. (2014) *Disablist Hate Crime (Briefing Paper 1)* [pdf] University of Leicester. Available at: https://www2.le.ac.uk/departments/criminology/hate/documents/bp1-disablist-hate-crime (Accessed: 18 June 2020).

The Wolfson Foundation (n.d.) *Funding for Museums and Galleries* [online] Available at: https://www.wolfson.org.uk/funding/funding-for-places/funding-for-museums-galleries/ (Accessed: 3 March 2022).

Thiemeyer,T. (2015). 'Work, Specimen, Witness: How different perspectives on museum objects alter the way they are perceived and the values attributed to them', *Museum and Society*, 13(3), pp. 396-412.

Titchkosky, T. (2014) 'Monitoring Disability: The Question of the "Human" in Human Rights Projects' In Gill, M., Schlund-Vials, C.J., Gill, A.P.M., Sherry, D.M. and Sherry, D.M. eds. *Disability, Human Rights and the Limits of Humanitarianism.* 1st ed. GB: Routledge Ltd. 99, pp. 119-136.

Turner, B.S. (2006) *Vulnerability and Human Rights,* First Edition. University Park: Pennsylvania State University Press.

UK Government (2010) *Equality Act 2010* [online] Available at https://www.legislation.gov.uk/ukpga/2010/15/section/6 (Accessed: 25 February 2022).

UN (Undated) *Human Rights* [online] Available at https://www.un.org/en/sections/issues-depth/human-rights/ (Accessed: 19 June 2020).

UN Enable (2007) *Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities* [online] Available at https://www.un.org/esa/socdev/enable/convinfofaq.htm#qi (Accessed: 18 June 2020).

UN General Assembly (2007) *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106 [online] Available at: https://www.refworld.org/docid/45f973632.html (Accessed: 12 May 2019).

Unikel, J. (2011) 'Staring Contest', *Disability Studies Quarterly,* 31(4) Available at: https://dsq-sds.org/article/view/1706/1787 (Accessed: June 10 2020).

V&A (2018) *Without Walls: Disability and Innovation in Building Design* [online] Available at: https://www.vam.ac.uk/exhibitions/without-walls-disability-and-innovation-in-building-design (Accessed: 10 April 2019).

Van de Wetering, J. (n.d.) *ABC OPEN: Advice animal memes for the disability community.* Available at: https://open.abc.net.au/explore/50348 (Accessed: 9 October 2017).

Visions: A History of the Royal School for the Blind, Museum of Liverpool, (n.d.) Exhibition Video, visited 09 March 2018.

Vizard, S. (2019) *Sainsbury's, NatWest and Nationwide gift Channel 4 ad airtime to disabled causes* [online] Available at: https://www.marketingweek.com/sainsburys-natwest-nationwide-channel-4-ad-airtime-disabled-causes/ (Accessed: 1 October 2020).

Vocaleyes (2020) *Ten Years of Progress* [online] Available at: https://vocaleyes.co.uk/ten-years-of-progress/ (Accessed: 3 March 2022).

Walshaw, M. (2008) *The Concept of Identity Positioning the Self within Research*, ICME 11 Proceedings pp. 322-337.

Webber, R. (2018) *Picturing Home: Exploring the Everday home-making practices of migrant, refugee and asylum-seeking women in Glasgow.* University of Leicester.

Weeks, L. (2015). *'Female Husbands' In The 19th Century*. [online] Available at: https://www.npr.org/sections/npr-history-dept/2015/01/29/382230187/-female-husbands-in-the-19th-century (Accessed: 14 May 2018).

Wellcome Collection (2019a) *About Us* [online] Available at: https://wellcomecollection.org/pages/Wuw2MSIAACtd3Stq (Accessed: 18 October 2019).

Wellcome Collection (2019b) *Being Human Opens* [online] Available at: https://wellcomecollection.org/pages/XW5QMBEAACUAELBV (Accessed: 28 October 2019).

Wellcome Collection (2019c) *Exhibitions: Being Human* [online] Available at: https://wellcomecollection.org/exhibitions/XNFfsxAAANwqbNWD (Accessed: 18 October 2019).

Wellcome Collection (n.d.) Item Label, visited 3 January 2020.

Wendell, S. (2013) 'Unhealthy Disabled: Treating Chronic Illnesses as Disabilities' In Davis, L.J. ed., *The Disability Study Reader,* 4th ed. Routledge, pp. 161-175.

Willis, S. (2016) "Testing Models of Working for Engagement and Participation" In McSweeney, K. and Kavanagh, J. eds. *Museum Participation: New Directions for Audience Collaboration,* Museums Etc., pp. 162-175.

Willitts, P. (2017) 'Bad attitudes do not cause disability any more than good attitudes guarantee health', *Philippa Writes,* Available at: http://www.philippawrites.co.uk/bad-attitudes-do-not-cause-disability-any-more-than-good-attitudes-guarantee-health/ (Accessed: 9 October 2017).

Wong, A. (2015, April 27) 'The Fight for Audio Description on Netflix's Daredevil' *Nerds of Colour,* Available at: https://thenerdsofcolor.org/2015/04/27/the-fight-for-audio-description-on-netflixs-daredevil/ (Accessed: 28 July 2020).

Woodside, A.G. (2010) 'Bridging the chasm between survey and case study research: Research methods for achieving generalization, accuracy, and complexity', *Industrial Marketing Management,* 39(1), pp. 64-75.

Wounded, Science Museum (n.d.) Exhibition panel, visited 01 November 2017.

Wordsworth, R. (2017, December 9) *The amazing bionic prosthetics that are changing lives and shaping our future.* Techradar. Available at: http://www.techradar.com/news/the-amazing-bionic-prosthetics-that-are-changing-lives-and-shaping-our-future (Accessed: 18 December 2017).

Wrona, T. and Gunnesch, M. (2016) 'The One Who Sees More Is More Right: How Theory Enhances the 'Repertoire to Interpret' in Qualitative Case Study Research', *Journal of Business Economics,* 86(7), pp. 723-749.

Young, S. (2014, April) *I'm not your inspiration, thank you very much* [Video]. TED Conferences.
https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much.