

**HOW CAN DISABLED PEOPLE BE EMPOWERED TO  
INFLUENCE DECISION-MAKING IN MUSUEMS?**

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# **How Can Disabled People Be Empowered to Influence Decision-making in Museums?**

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## **Abstract**

At the centre of this piece of research is a case study that focused on a group of young disabled people who worked with The Holocaust Centre, Nottinghamshire, on a longitudinal ethnographic piece of action research. The aim behind this study was to support the young people to work with the Centre to challenge exclusionary practices. Opened in 1995, the Centre explores the history of the Holocaust and its implications for contemporary society. However, significant physical, sensory and intellectual barriers were built into the Centre that prevented disabled people from fully engaging with its site, facilities and programmes. For a place that discusses issues of prejudice and exclusion, its core values were clearly at odds with its daily operational practices.

This study applied a research paradigm from the field of disability studies, which had been developed in response to the historic exclusion of disabled people from the research process, to the museum context. Emancipatory disability research principles focus on issues of reciprocity, empowerment and gain, and are intended to ensure that disabled people are in control of the research agenda. This study thus investigated whether by following these principles it was possible to support the young disabled people to empower themselves through research, and whether they directly benefited through their involvement in it. The study also explored whether this approach enabled them to gain access to decision-making by working in partnership with the Centre to challenge exclusionary practices.

Addressing a significant gap in literature, this thesis speaks to the wider sector, as it explores how museums can work in more equitable ways with communities to address inequalities of power, whilst focusing on the issues that contribute to individuals' and communities' marginalisation. It therefore examines how issues of oppression and exclusion can be addressed through strategies that promote their empowerment.

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## List of Abbreviations

AHRC	Arts and Humanities Research Council
CAQDAS	Computer-Aided Qualitative Data Analysis
DCMS	Department for Culture, Media and Sport
DDA	Disability Discrimination Act
DPI	Disabled People's International
DST	Nottinghamshire County Council Youth Services Disability Services Team
GLLAM	Groups for Large Local Authority Museums
LGBT	Lesbian, Gay, Bisexual and Transgender
MLA	Museums, Libraries and Archives Council
RCMG	Research Centre for Museums and Galleries
SMC	Scottish Museums Council
THC	The Holocaust Centre
UNDP	The United Nations Development Programme
UPIAS	Union of Physically Impaired People Against Segregation
V&A	Victoria and Albert Museum

## Introductory Chapter

The case study at the Centre of this thesis began as a matter of complaint.

Margaret Clement, Senior Youth Worker and Team Manager for

Nottinghamshire County Council Youth Services Disability Support Team

(known as DST), visited The Holocaust Centre (THC), Nottinghamshire in 2006

on an 'opening evening' and was concerned about the range of physical, sensory and intellectual barriers to access that she encountered on the site.

Reflecting on this visit,<sup>1</sup> Margaret discussed the initial conversation that she engaged in with a member of the Centre staff in order to raise her concerns:

I was a bit stunned really! [...] I spoke to [a member of staff]<sup>2</sup> and raised the issues [...] and she hadn't got an answer to that. She suggested I organise a conference at the Holocaust Centre. [...] It's like well you solve it then. [...] So I came away thinking, well, I don't want to organise a conference! [...] I just want to bring young people, but I can't.

Margaret was concerned that rather than enter into a discussion that acknowledged the consequences of the access issues, the member of staff had deflected responsibility back to her. This overlooked the Centre's responsibilities, in particular as it was a place that aimed to discuss issues of prejudice and exclusion (Smith 2002; THC 2005a; 2007a; 2012a).

When questioning whether it matters if marginalised communities are excluded from museums, it can be argued that communities such as disabled people have a fundamental right to access culture. As stated at the United Nation's World Conference on Human Rights: 'all human rights and fundamental freedoms are

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<sup>1</sup> A list of interview data collected in the study can be found in Appendix 1. The name of the person interviewed and the date of recording is included.

<sup>2</sup> Following best practice, informed consent was obtained from all participants in the study. Some staff at the Centre did not want to be named in the thesis. However, the Chief Executives agreed to be named. Therefore, all staff below Chief Executive level have been anonymised.

universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same right to life and welfare, education and work, living independently and active participation in all aspects of society' (United Nations 1993, 23). However, Oliver (1990), a leading academic in the field of disability studies, contends that disabled people have been denied access to the key political, educational and cultural institutions that could enable them to fully participate in society, and that this exclusion has resulted in their marginalisation. It can be argued that museums are one of the major cultural institutions contributing to disabled people's marginalisation through their exclusionary practices.

## **Research Question and Aims**

The overarching research question that the study addressed is: How can disabled people be empowered to influence decision-making in museums?

Although this single, in-depth case study focuses on a Holocaust museum and its exclusionary practices that affect disabled people, it also seeks to demonstrate that its outcomes have wider implications for the museum sector and its work with marginalised communities.

To answer the question, the research draws on the emancipatory disability research principles developed within the academic field of disability studies, which together form an underpinning paradigm to guide the philosophical and practical development of the study. These principles were developed in response to the historical exclusion and exploitation of disabled people within academic research (Hunt 1981; Barnes 1992a; Oliver 1992; Zarb 1992).

Therefore, this paradigm, derived from within disability studies, is applied to the

museum studies context. Moussouri (2007) reported on a museum adult learning project that aspired to follow some of the emancipatory principles in the planning of its programme. However, this was the first documented case of these principles being applied to the planning, implementation and analysis of a piece of museum studies research.

As is discussed later in the thesis, the secondary research questions aim to examine the facets of the overarching question and focus on the process of undertaking this methodology, considering the impact and outcomes for all parties involved. Fundamentally, this study explores whether it is possible to challenge inequalities through the use of emancipatory disability research principles. Therefore, it is interested in the influence that research can have on museum practice, and how the disabled people involved in the study benefited from their involvement. At the heart of this piece of research are issues of reciprocity, gain and empowerment (Oliver 1992). By following these principles, researchers should aim to address the power inequalities that can occur within the research process, so as to support disabled people in taking control of the research agenda.

The thesis draws on the museum literature that focuses on how communities can be excluded from society, and how museums can act as agents of social change (Sandell 1998; 2002a; 2003; 2007; Newman 2001; Newman and McLean 2004a; 2004b; Silverman 2002; Janes and Conarty 2005). In contrast to the wealth of material addressing this issue, less is written about how museums can support oppressed people to challenge power inequalities. There are many calls within the literature for museums to take on this role (Sandell 2007; Witcomb 2007; Silverman 2010); however, little is written on the specifics of how

museums can go about supporting communities to empower themselves and enact change. This thesis thus addresses this gap in the literature and, by following a methodology that was designed to support disabled people's empowerment, it analyses whether this methodology can be utilised to challenge power inequalities within museums.

## **Methodology and Case Study**

The Holocaust Centre was founded in 1995 by the Smith family (Smith 2002) with the aim to explore the history of the Holocaust and its implications for contemporary society (THC 2012a). Developed in response to the family's visits to Yad Vashem – the Holocaust memorial museum in Jerusalem – (Smith 2002), the Centre is an independent museum which receives no core funding from local or national government (THC 2012b). It was set up on the site of the family's home in rural Nottinghamshire as Britain's first dedicated Holocaust centre, and includes a memorial hall, Holocaust exhibition, memorial gardens and café (see figures 1 and 2). As described on its website, it is a place of education, memory and testimony (THC 2012c). During the time period of the fieldwork (January 2007 to October 2008), the Centre welcomed an average of 20,000 visitors per year, most of whom were secondary-school children whose study programme centred on meeting a survivor of the Holocaust (THC 2007b).



**Figure 1: Sculpture representing six death camps. The memorial rose garden is seen in the background<sup>3</sup>**



**Figure 2: The Centre and gardens. The Centre is seen in the background behind the memorial garden's dovecot. The main building at the Centre is called 'Beth Shalom – 'House of Peace' in Hebrew**

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<sup>3</sup> All photographs are author's own unless otherwise specified.

The Centre and its 'sister' organisation, The Aegis Trust,<sup>4</sup> have made significant contributions to the fields of Holocaust and genocide studies/education through their work to help survivors come to terms with traumatic events in their lives, their education programmes and their work to lobby on issues related to contemporary genocide prevention. However, the post of Access Officer that I performed at the Centre was intended to address the substantial physical, sensory and intellectual barriers that had been built into the site, limiting disabled people's access to its building, facilities and programmes (THC 2005b). On the one hand, the Centre has a long history of supporting the Jewish community who have been affected by extreme prejudice and exclusion; on the other hand it was discriminating against disabled people on institutional and daily operational levels.

In 2005, I took up the post as the Centre's first Access Officer, and went on to undertake the role of Senior Access and Collections Manager. In my equalities role I was the member of staff who responded to the letter of complaint, written by Margaret Clement's line manager, which highlighted her concerns about disability access at the Centre. As a consequence of the subsequent meeting to discuss these concerns, the Nottinghamshire Pioneers Youth Forum (known as the Pioneers) (see Figure 3) agreed to work with the Centre on a piece of action research. The purpose of the Pioneers group is to provide 'an opportunity for young disabled people to have a voice in different aspects of their lives' (DST 2009, 3), and the longitudinal study that developed followed critical ethnographic

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<sup>4</sup> Established in 2000, The Aegis Trust campaigns against crimes against humanity and genocide. Meaning 'shield' or 'protection', Aegis developed from the work of the Centre, and is responsible for the Kigali Genocide Memorial in Rwanda, created in partnership with the Rwandan people to help them come to terms with their recent traumatic history. With an international focus, Aegis's activities include: research, policy, education, remembrance, media work, campaigns and humanitarian support for victims of genocide (The Aegis Trust 2012).

and emancipatory action research methodologies. This in-depth piece of research enabled the Pioneers to challenge exclusionary practices at the Centre through the research. This approach raised issues in relation to the subjective and political nature of the study, however, which are explored later in the thesis. The combination of participant observation, documentary sources, photographic records and interviews allowed the unfolding process of undertaking emancipatory research to be captured.



**Figure 3: The majority of the core members of the Pioneers' group. Left to right: Margaret Clement (Senior Youth Worker), Laila Dannourah, Lorraine Quincey, Audrey Gardner (Youth Worker), John Georgehan and Keiron Stobbs**

The choice of research methods utilised with the Centre staff was more problematic, due to the need to balance my professional role at the Centre with the role of researcher. As discussed by Blaxter, Hughes and Tight (2010), the process of undertaking research in your workplace can be challenging, and tracking the staff developments in the same way as tracking those of the Pioneers was deemed to be unrealistic. Instead, data collection focused on

reflective interviews at the end of the fieldwork and the collation of documentary sources and photographic records. This combination enabled a rich data-set, to be collected and analysed as discussed by Geertz (1973).

## **Structure of the Thesis**

Chapters 1 to 3 explore the theory, literature and terminology that underpinned the research question, the choice of methodologies/methods and the approach to the analysis. Before focusing on matters relating to disability and museums, Chapter 1 looks more broadly at the ways in which people can be excluded and marginalised within society. This chapter briefly explores the nature of social exclusion before moving on to a more central focus on issues of oppression and how they relate to issues of power. This provides a backdrop to a discussion about the way that marginalised communities can be supported to empower themselves.

Chapter 2 explores how the term disability is defined and conceptualised and how key academics within the field of disability studies have created a series of models to explain the way that people think about disability. It examines the current model that is favoured by the UK disability movement, the social model of disability, and its implications for the research.

Chapter 3 draws on the broad issues of social exclusion, oppression and disability, and applies them to the museum context. It also demonstrates how museums do not always prioritise issues of inequality at their core and conversely, how pioneering museums can be willing to take risks to invite

external groups into their organisation on a more equal footing. It therefore explores themes of inclusion, participation and power-sharing.

Chapter 4 discusses the philosophies and principles that underpin the research, as well as the historic exclusion of disabled people from the research process. It examines how key academics from the field of disability studies responded to these issues of exclusion through the creation of the emancipatory disability research paradigm. Given this context, the rationale behind the research questions is examined, along with the approach to the case study. These factors give the context for the choice of methodologies and methods and the ethics of conducting research with young disabled people.

Chapter 5 analyses the process of implementing the emancipatory principles during the fieldwork. It deconstructs the steps involved in the Pioneers becoming informed decision-makers, and discusses how the group took control of the research agenda. It explores the direction that the research took, and the extent to which the study was able to follow these emancipatory principles.

Chapter 6 deconstructs the impact of the research on the Pioneers, the youth workers, the Centre staff and the organisation as a whole. It focuses on whether the Pioneers were supported to empower themselves through the research, and whether they directly benefited from their involvement. It moves on to look at the factors that influenced changes to staff working practices, and the impact that the Pioneers had on the Centre.

The concluding chapter examines the main issues that arose from conducting a piece of emancipatory disability research and their relevance to the wider museum sector's work with marginalised communities. It investigates the

disability-specific issues highlighted by the study, before looking at the additional implications for research practices and the field of disability studies. Finally, it considers the impact of the thesis on my own professional practice, before summing up the contribution that the study makes to anti-oppressive practices that museums can engage in to address social inequalities.

# **Chapter 1: Social Exclusion, Oppression and Empowerment**

## **Introduction**

This chapter investigates the broad base of theory and literature that seeks to explain how some individuals and communities can be marginalised within our contemporary UK society. Beginning with an examination of the nature of social exclusion, it charts the rise of the terminology defining exclusion, and how exclusion can be tackled by activities that promote social inclusion. It then moves on to consider issues of power and inequality, and how power is relational in nature. Drawing on the work of authors such as Foucault (1980; 1990; 2005; 2006) and Lukes (2005), this chapter explores how power is linked to powerlessness and oppression. The discussion also draws on the work of authors from the fields of sociology (Byrne 2000; Butler and Watt 2007), social work (Solomon 1976; Thompson 2001; Adams 2003), social care (Braye and Preston-Shoot 2003; Dalrymple and Burke 2006) and health (Wallerstein 1992; Wallerstein and Bernstein 1994; Anderson 1996). Demonstrating how key authors have proposed that these issues can be tackled through approaches designed to support people's self-empowerment, the argument draws on the work of Freire (1972), whose publication 'The Pedagogy of the Oppressed' lays out a framework to teach oppressed peoples ways to challenge disempowerment. The broad societal issues outlined in this chapter will be revisited throughout the thesis, as they inform debates in disability studies and museology.

## The Nature of Social Exclusion

As discussed by Morgan et al. (2007), the term 'social exclusion' was first introduced into French political and academic discourses by Lenoir (1974) to describe people who were excluded from the social insurance system. Groups that were identified as socially excluded included disabled people, lone parents and the unemployed. He identified that 'the excluded' (*les exclus*) were prevented from participating in a broad range of social and economic activities (Saunders, Naidoo, and Griffin 2007). Citing Berghman (1995), Butler and Watt (2007) describe how the term became integrated into French social policy in the 1980s, with its usage becoming widespread across governments in the European Union. However, Murard (2002) criticises the widespread uptake of the term, asserting that it is an 'empty box' which can be used to encompass a whole range of social issues.

Initially, its scope was poorly demarcated. Citing Levitas (1998) and Watt and Jacobs (2000), Butler and Watt (2007, 111) describe how it is an 'umbrella' term for 'a large number of quite distinct phenomena, ranging from poverty, unemployment and racism to crime and "anti-social behaviour"'. However, the evolution of the term marked an attempt by these authors to encapsulate the very real social circumstances that individuals or even whole communities found themselves living in. The aim to delineate this term was not merely to define these circumstances, but also to identify the root causes within society so that the government could tackle them.

By the 1990s, the term social exclusion had been adopted across UK social policy, 'not only in the processes of policy development but also at the sharp end

of policy implementation' (Byrne 2000, 1). The focus on social exclusion came to the fore after New Labour was elected in 1997. Byrne (2000) describes how New Labour set up the Social Exclusion Unit with a specific mandate to explore the underlying causes behind social exclusion, and create policy as a basis for programme development to combat the identified issues. As described by Hills and Stewart (2005) New Labour's implementation of this broad social policy programme was intended to tackle a wide range of social issues, including child poverty, long-term unemployment, deprivation and inequalities in health and educational attainment. In 2001, the unit created a comprehensive description of the interlinked factors behind exclusion:

Social exclusion is something that can happen to anyone. But some people are significantly more at risk than others. Research has found that people with certain backgrounds and experiences are disproportionately likely to suffer social exclusion. The key risk-factors include: low income; family conflict; being in care; school problems; being an ex-prisoner; being from an ethnic minority; living in a deprived neighbourhood in urban and rural areas; mental health problems, age and disability (Social Exclusion Unit 2001, 11).

Although the Social Exclusion Unit's (2001) definition more clearly demarcates the term, the wording is quite impersonal. What is missing is a sense of what exclusion actually means for individuals. What are they actually excluded from? What is the impact on their lives? Howarth et al. (1998) get closer to conceptualising the issue by identifying 46 indicators of social exclusion, including children living in workless households, suicides among young people and anxiety in older people. These categories start to indicate how difficult it can be for people living in these circumstances to escape the situations in which they live, due to the interlinked and deep-seated nature of the issues that shape their lives. The Joseph Rowntree Foundation report, 'Poverty and Social

Exclusion in Britain' (Gordon et al. 2000), identifies that out of the 58 million people in the UK in 1999, approximately 9.5 million could not afford adequate housing conditions, and 7.5 million were too poor to engage in common social activities such as visiting friends and family. Significantly, a third of British children went without at least one of the things they needed, such as three meals a day, toys or adequate clothing. Although the report is over a decade old, a more up-to-date study is not available for examination. A decade ago, the economy situation was stronger, and therefore one might speculate that current conditions are even worse for the UK population.

The Joseph Rowntree Foundation report goes beyond material issues of poverty identifying human rights, customs, social obligations and social activities that people were unable to engage in to lead a decent quality of life. Levitas et al. (2007, 9) summarise the issues involved in exclusion, and add a cultural dimension to their definition:

Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities available to the majority of people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.

Byrne (2000) and Dodd and Sandell (2001) also assert that culture is a dimension of social exclusion, with Dodd and Sandell (2001) stating that it is relatively straightforward to situate museums within the cultural arena of exclusion. As cultural institutions that reflect society, museums can exclude people on a number of levels, as will be discussed in Chapter 3.

However, although a significant percentage of people in UK society can be classed as socially excluded, Butler and Watt (2007) claim that the data on

exclusion does not point to an 'underclass' of people who are permanently excluded. Burchardt, Le Grand and Piachaud (2002) see social exclusion in terms of a continuum (rather than a binary issue): at one end of the scale there are people excluded from society, and at the other there are people fully included. From this perspective, if a child is born into a family which is affected by exclusion they are not necessarily trapped in this position for life. Indeed, emancipatory research aims to empower people to gain the knowledge and skills needed to change their circumstances, as will be discussed in Chapter 4.

### **What Is Social Inclusion?**

As discussed, when examining how to tackle social exclusion authors such as Burchardt, Le Grand and Piachaud (2002) state that exclusion and inclusion exists on a continuum. The Charity Commission (2001, 2) guidance document on the promotion of social inclusion explains that it can be achieved through 'positive action taken to change the circumstances and habits that lead, or have led, to social exclusion. It is about enabling people or communities to fully participate in society'. The document identifies the need to support socially excluded individuals and communities to overcome inequalities and disadvantage, and to promote equality of opportunity. The Commission also identifies the need to address the specific issues behind the individual's or community's exclusion. Chapter 3 explores how museums have responded to this agenda, and focuses more centrally on how the exercise of power is important when considering how people are marginalised within society. The literature on social exclusion does not centrally engage with issues of power, or how individuals and communities can be marginalised due to power inequalities

in society. Therefore, it is important to draw on the literature in relation to how power inequalities can lead to oppression, and to individuals and communities feeling powerless.

## **What Is Power?**

To understand oppression and powerlessness it is first important to focus on power and how it is exercised over others. In the literature, many authors (Foucault 1990; 2005; Wallerstein 1992; Lukes 2005) discuss the relational nature of power. Wallerstein (1992) identifies that powerful individuals or groups in society have the 'power to act' and the 'power over' others. Conversely, other people are left in a position of powerlessness (a deficiency in power) and feel disempowered (as they lack agency). As Lukes (2005) discusses in his important publication *Power: A Radical View*, this also means that people who possess power will have a greater range of choices in a given situation than those who are disempowered, as those in power are in control of the decision-making process. This view is in alignment with another key author, Foucault, who regards power as something that can be exercised rather than a commodity to be possessed (Foucault 2006). Foucault (1990) argues that power is more complex than a case of one group oppressing another. Instead, he argues that power is productive, 'that it generates a particular type of knowledge and cultural order' (O'Farrell 2005, 100). This is of interest in the context of museums, as it links to the argument put forward by Bennett (1995) in his book *The Birth of the Museum* in which he explains how power is intertwined with the knowledge that museums assign to objects. He discusses the exhibitionary power of museums, and how they have historically been used as a way of establishing the power of

the ruling class. The power that museums have to include or exclude individuals and communities will be considered in Chapter 3.

As described by O'Farrell (2005), Foucault rejects the idea that power is only held by institutions like the State. Foucault (1990) and Lukes (2005) argue that power is not a static, fixed entity; similarly, Abercrombie and Longhurst (1998) draw on Foucault to argue that power is fragmented, situated and dynamic within society. Lukes (2005) describes how one group's power can increase or decline. From this perspective power is an ever-changing and fluid entity that occurs at all levels in society. What interests Foucault (1990; 2006) is how power is exercised through social relationships and he asserts that power is exercised on a daily basis in a myriad of different social relationships. Radtke and Stam (1994) agree suggesting that all social practices are shaped by power. The ability to navigate these power relationships is complex, with Solomon (1976) viewing power as an 'interpersonal phenomenon'. This is of particular interest to this study, which aims to support the Pioneers to influence decision-making at The Holocaust Centre, which involves navigating the power structures involved in interpersonal relationships.

Foucault (1990) discusses the relationship between power, oppression and resistance. In the application of his ideas he shows that people who are in powerless positions do not necessarily need to accept these positions, but they have the capacity to resist authority and challenge its decisions. As will be discussed in the analysis of the data in chapters 5 and 6, this is pertinent to the Pioneers engagement with the Centre and their aim to challenge exclusionary practices. This matter of how individuals and groups can exert an influence in society is described by Bourdieu (1986; 1997), Colman (1988; 1990), Bourdieu

and Wacquant (1992) and Putnam (1993; 2000) in terms of 'social capital'.

Although these authors have differing interpretations of what this term means, they all share the central idea that there is value in the social networks that exert an influence in society. Newman and McLean (2004a) and Newman (2006a) apply the notion of social capital to the museum context, with Crooke (2007) explaining how the involvement of excluded communities in the management of museums can improve the provision of facilities, leading to more appropriate use of resources. This issue will be examined as part of this thesis, as the Pioneers needed to build up enough social capital to influence the Centre to make changes.

Lin (2001) usefully links social capital to the workplace, and considers how social ties may influence the decision-making of people in positions of power. She asserts that social ties and relationships affect people's ability to influence decision-making within organisations, and that social capital carries a certain weight in this process. Although Lin is referring to employees within corporate structures, her ideas apply to the influence external agents can have on museums. Individuals or communities with greater social capital will be in a better position to sway decision-making than those that lack this resource. Therefore, the issue of social capital will be drawn upon in the analysis of the data in Chapter 6.

Having established that power is a two-way relationship and that it can occur in a myriad of social relations at different levels of society, it is easier to understand how people can be disempowered by social relationships. This exertion of power over others is the basis upon which oppression can operate within society.

## The Nature of Oppression

The discourse about oppression is rooted in a long history of communities that are affected by prejudice such as the black community, women, disabled people and the Lesbian, Gay, Bisexual and Transgender community (LGBT) (Braye and Preston-Shoot 2003). This discourse is linked to the civil rights movements which were formed by these communities in order to forward their rights and improve their position within society. If social exclusion can be seen in social, political, economic and cultural terms (Dodd and Sandell 2001), oppression can be viewed in terms of power relationships within society. Debates about oppression also involve an exploration of how people can challenge power inequalities. Two linked issues that are important when discussing oppression are the nature of power and powerlessness. Related to these is the matter of how individuals and communities can be 'freed' of oppression through their self-empowerment. The next sections of this chapter will unpack these issues in more detail.

When focusing on oppression, it is important to first explore what is meant by the term, as it is significantly different to how social exclusion is understood. Dalrymple and Burke (2006, 40) assert that there is 'no simple definition of oppression. It is a complex and emotive term. To seek to identify and explain it in a simple phrase is to deny its very complexity'. Dalrymple and Burke come from the field of social work, and social work and social care offer much to the understanding of how particular groups are oppressed, as social workers come in contact with some of the most vulnerable and marginalised people in society. However, Thompson (2001, 34), another author from the field of social work, offers a broad definition of oppression which tries to capture the multilayered

nature of the terms, as the: 'Inhuman or degrading treatment of individuals or groups; hardship and injustice brought about by the dominance of one group over another; the negative and demeaning exercise of power. Oppression often involves disregarding the rights of an individual or group and is thus a denial of citizenship'. This definition not only outlines the relational issues of power, but also shows how, when it is exercised over others, power can deny people their rights and even their dignity.

McNay (1992) and Clifford (1998) indicate that this can occur at family, group, community or societal levels and as Dalrymple and Burke (2006, 41) go on to say: 'The interactive nature of oppressive relations means that they are continually reproduced within daily individual activities and social systems'. Therefore, individuals can experience it in all areas of their daily lives and the impact can be all-consuming. Dalrymple and Burke expand on this, explaining that oppression 'can be specific in that it is manifested in one form or another, such as racism, sexism, heterosexism [and] disablism' (2006, 43), and that these forms can be interconnected and then internalised by the individual. This issue of the internalisation of oppression is discussed in the social work literature by Solomon (1976), and in the disability literature by Reeve (2002; 2004) and Thomas (2002; 2004a). As discussed by Dalrymple and Burke (2006), it is clear that certain groups of people are more likely to be affected by inequalities of power than others. Price (1996) asserts that modern notions of power are associated with white, male, physically able bodies, and it can be argued that middle class, heterosexual, able-bodied men are the least likely individuals in society to be affected by oppression. Having established that

disabled people are one of the groups that can be affected by oppression, Chapter 2 will explore this issue in more detail.

Macpherson (1999), Singh (2002) and Heron (2004) all raise the issue of how oppression can operate on an institutional level. The Macpherson Report (1999) was the culmination of the 1998 public inquiry into failings in the Metropolitan Police Service's investigation into the death of Stephen Lawrence, a black teenager. It concluded that his death had not been properly investigated due to deep-seated racist practices within the police force that amounted to 'institutional racism'. Macpherson defined institutional racism as 'the collective failure of an organization to provide an appropriate and professional service to people because of their colour, culture and ethnic origin' (1999, 28). This definition can be widened to cover other forms of oppression, and this institutional level of oppressive practices can be applied to the museum context. If we accept that people who work in museums can intentionally or unintentionally oppress people from marginalised communities through their working practices, it becomes important to identify how working practices can be changed to address this issue.

In a social work setting, this understanding has been applied to anti-discriminatory work intended:

to reduce, undermine or eliminate discrimination and oppression, specifically in terms of challenging sexism, racism, ageism and disablism. [...] Anti-discriminatory practice is an attempt to eradicate discrimination and oppression from our own practice and challenge them in the practice of others and the institutional structures in which we operate (Thompson 2001, 34).

It is worth noting that within the field of social work the terms 'anti-discriminatory' and 'anti-oppressive' practices are sometimes used interchangeably. However,

there is an important distinction to be made between the two terms as explained by Phillipson (1992). She indicates that anti-discriminatory practice focuses on the removal of barriers to access from within the existing power structures of an organisation. Anti-oppressive practice, on the other hand, is more radical as it aims to challenge the existing power structures and exploitative relationships which can create oppressive practices. Moving back to Thompson's (2001), it can be seen that the definition includes elements of anti-discriminatory and anti-oppressive practices.

On a final but important note about the nature of oppression, Freire (1972) and Dalrymple and Burke (2006) all discuss the need to consider issues from the perspective of people who are affected by oppression. Dalrymple and Burke (2006, 39) state that: 'It is from the experiences of people who have been marginalized, who have had their rights denied or violated, that we can understand what is meant by oppression'; with Freire (1972) additionally asserting that oppressed peoples must believe that they can change their lives. Mirroring these ideas in the disability literature, Morris (1991a) discusses the value that should be placed on disabled people's embodied knowledge of their impairments, and how oppressive practices can affect them.

## **The Nature of Powerlessness**

Solomon (1976), a key author in the field of social work, whose publication *Black Empowerment: Social Work in Oppressed Communities* focuses on black communities in the USA, indicates that one of the main reasons why communities remain in oppressed and disempowered positions is due to issues of powerlessness. Solomon asserts that: 'Powerlessness of black individuals,

groups, and communities arises through a process whereby valued identities and roles on the one hand and valuable resources on the other are denied, all of which are prerequisite to the exercise of interpersonal influence and effective social functioning' (1976, 11). In other words, Solomon identifies that powerlessness occurs within the black community due to the denial of resources, and the negative perceptions that society places on this community. The issue of powerlessness can thus be applied more widely than to the black community, as it affects other marginalised groups. Solomon expands on the matter by stating that power deficiency stems from a complex and dynamic interrelationship between the person and hostile social relationships, as well as the ways this interrelationship interferes with the process of human growth. This is clearly a multifaceted issue, and Solomon elaborates by describing how oppression disrupts the acquisition of the skills needed to successfully negotiate power. She describes three levels of 'power blocks' that can affect individuals:

At the primary level, negative valuations or stigmas attached to racial identification become incorporated into family processes and prevent optimum development of personal resources as described above; i.e. positive self concepts, cognitive skills, etc. At the secondary level, power blocks occur when personal resources that have been limited by primary blocks in turn act to limit the development of interpersonal and technical skills. At the tertiary level, power blocks occur when limited personal resources and interpersonal and technical skills reduce effectiveness in performing valued social roles (1976, 17-18).

So, a black person may internalise negative ideas about their identity (stigma) through the messages that they receive from their family, peers and wider society. This can lead to poor self-esteem and poor engagement with educational attainment which can in turn limit the acquisition of the qualifications and skills needed for employment. At the tertiary level, these combined issues limit the opportunities for black people to perform valued social roles, and

therefore exert an influence within society. Of course, these issues are more complex than have been outlined here, and the progression is not necessarily so linear. However, it shows how oppression can invade large areas of people's lives and leave them in disempowered positions.

Although Solomon discusses power blocks in the context of the black community, the three levels she identifies could be applied to any marginalised community, given that people who are marginalised tend to be affected by stigma, which relates to their identity. The internalisation of stigma can lead to issues of poor self-esteem, and a limited ability to negotiate power relationships. The idea of people being prevented from exerting an influence in society, and therefore negotiating power relationships, links to the concept of social capital, as discussed earlier in this chapter.

Solomon explores how it is difficult for people in powerless and oppressed positions to change their circumstances, as these issues become part of every area of their lives, and frame the ways that other people view them. Yet, although Solomon examines powerlessness, the main focus of her work is, conversely, on empowerment, and on how to support black people to gain the personal and technical skills needed to challenge oppression. She discusses empowerment as a mechanism to remove the power blocks that keep people in a position of powerlessness. For example, she outlines the importance of social work as a way to support black people to empower themselves, rather than as a process whereby social workers make changes on their behalf. This is an important issue for this study, as it raises the question of whether emancipatory disability research principles can support a group of young disabled people to empower themselves.

## What Is Empowerment?

The term empowerment has created much debate in the literature. Humphries (1996, 1) criticises the literature on empowerment as being 'reductionist' or 'simplistic', as it implies that empowerment is 'simply a matter of will, either on the part of those who are disempowered, or on the part of those in a position to empower'. However, the reasons why people are in powerless positions stem from complex interlinked factors and, therefore, it is not merely a matter of willpower, as change involves both agency and action.

When thinking about what is meant by empowerment, it is useful to go back to Solomon (1976), whose work so centrally revolves around this issue. She defines it as an active process: 'Empowerment refers to a process whereby persons who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skills in the exercise of interpersonal influence and the performance of valued social roles' (1976, 6). Solomon identifies that the active element of this process is the acquisition of skills to enable people to exercise influence. Many authors (Rappaport 1987; Wallerstein and Bernstein 1994; Anderson 1996) consider empowerment as a process rather than an outcome, that the learning and the changes which take place during this process are sometimes more important than the outcome. In contrast, other authors (Swift and Levin 1987; Holdsworth 1991; Sohng 1998) view empowerment as a goal, product or outcome. It could be argued that both positions have validity, and Chapter 5 will explore the process of undertaking work that focuses on empowerment, whilst Chapter 6 will examine the outcomes of that process.

Like power, the process of empowerment is relational and involves interplay between people or groups in society. On this issue, Anderson (1996, 80) asks: 'When looking at outcomes, we have to ask who gains and who loses', as some groups can be empowered at the expense of others. As will be discussed from the disability perspective in Chapter 2, in any given situation the position of oppressor and oppressed is not a clear-cut binary issue. Nonetheless, the benefits of empowerment, when seen, can be great. For Wallerstein (1992), empowerment involves an active process of people gaining control, and the power to improve both their quality of life and their political position within society. Anderson (1996, 81) qualifies this issue by stating that: 'Social change may benefit many people in a community, particularly those who participated in social action. Those individuals who give time and energy may gain most, in terms of increased skills, confidence and sense of individual power'. It follows that the people directly involved in activities which focus on empowerment will benefit most from their involvement. However, other authors (Rappaport 1987; Anderson 1996; Adams 2003) suggest that the outcomes of empowerment activities may have a wider impact on communities, an idea which will be discussed in more detail in the next section.

For the people involved in activities that aim to empower people, Wallerstein and Bernstein (1994) raise a note of caution: that set-backs and frustrations with the process might have the converse effect of making people feel more powerless if changes do not occur. Anderson indicates that 'empowering social action at a local level will not always lead to noticeable positive social change' (1996, 80). This may be due to the complexity of trying to alter social relationships, and

because people in positions of authority may not necessarily want to share or hand-over power.

Overall, it is clear that empowerment is a complex process and, when considering how to effect change and support people to empower themselves, the literature does not offer easy solutions or step-by-step strategies to follow. Wallerstein (1992) states that there is no perfect model of empowerment. This is due to the complexity of the issues involved in tackling exclusion and oppression. Chapter 4 will look at how the use of emancipatory principles might support the Pioneers to empower themselves through this piece of action research, and the issues outlined in this current chapter will be of benefit to the analysis of the data collected in the study. Now that the nature of empowerment has been established, the next section will move on to look at how empowerment can work on different levels in society.

### ***Levels of Empowerment***

A number of authors discuss the levels at which empowerment can occur within society (Rappaport 1984; Anderson 1996; Adams 2003; Dalrymple and Burke 2006). Adams (2003) describes five levels: individual, interpersonal, group, organisational and community. This concurs with Rappaport's (1984) view that empowerment is a multifaceted and multidimensional process that occurs on a number of levels. Anderson (1996, 70) states that individual empowerment as: 'Individual or psychological empowerment can either be seen to be a quality similar to self-esteem, or as feelings of greater control that individuals gain following active membership of organisations'. She expands on this issue by explaining that community empowerment includes the above elements, 'along

with political action towards redistribution of resources' (1996, 70). Therefore, individuals who are involved in empowerment can be personally empowered whilst effecting change on other levels. Dalrymple and Burke (2006, 113) clarify how this issue relates back to oppression:

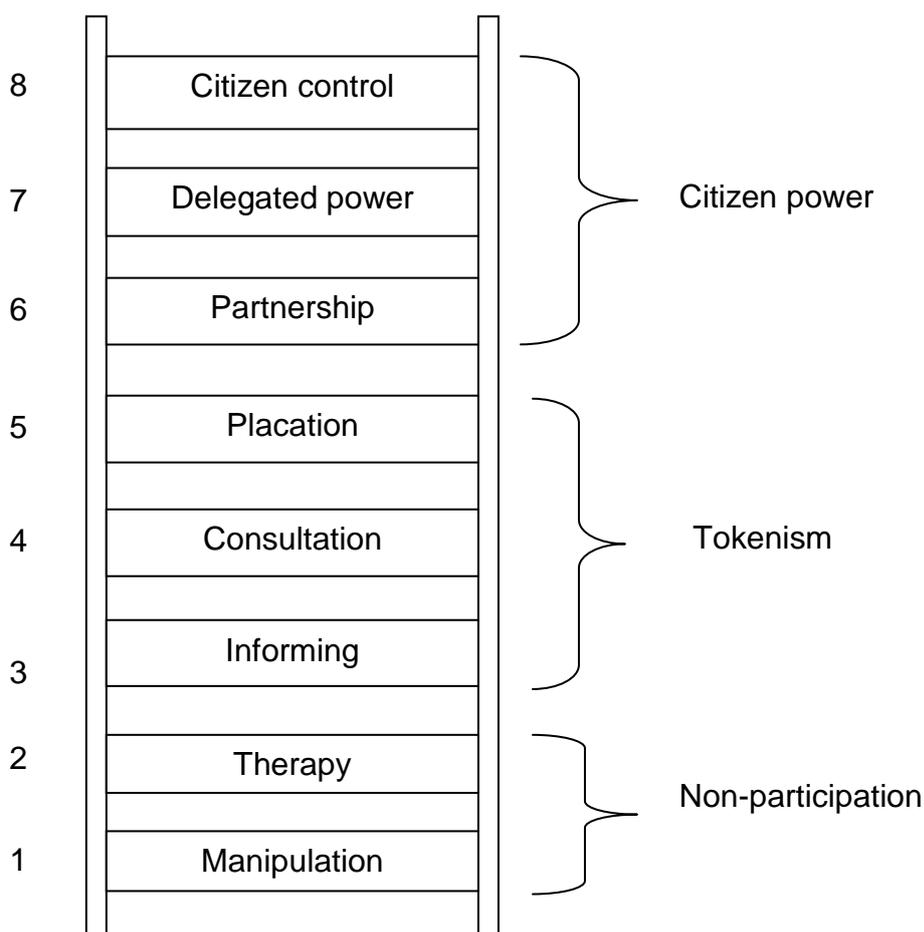
Individuals who make the connections between their personal condition and the society in which they live begin to make changes within themselves, within their families and community and wider social structures. People who become aware of the connection between their personal condition and the society in which they live have the means to evaluate their position critically. Through this process of self-discovery we are able to name our oppression, but equally we can begin to address the causes of our oppression.

This statement creates a powerful link between the personal process of empowerment and how it affects the community around the person. It demonstrates how greater personal awareness can lead to change. As will be seen later in this chapter, these ideas are echoed in the work of Freire (1972).

A final way of looking at empowerment which is useful to this thesis is presented by Arnstein (1969). Arnstein's 'Ladder of Citizen Participation' (see Figure 4) looks at the degree to which people are involved in the planning and implementation of changes within organisations.

The bottom two 'rungs' of the ladder can be classed as non-participatory. Arnstein describes them as actions that are 'done to people', as the goal is controlled by the initiator. She views these forms of engagement as activities that pay 'lip service' to the individuals involved, as the initiator does not aim to share power with the participants. Arnstein describes how at this level the views of the citizens are not taken into consideration, and that their engagement is more about 'rubber stamping' the organisation's views on matters. The third rung is a step upwards, as it involves the sharing of information with participants.

However, communication is one way, as the participants' views are not sought in return.



**Figure 4: Arnstein's 'Ladder of Citizen Participation' (1969)**

The fourth and fifth rungs on the ladder begin to involve participants, albeit in a tokenistic way. As Green (2007) notes, Arnstein uses the term 'placation' to describe how organisations can engage in consultation in a way that appears to be a dialogue, but how in reality they are not interested in addressing the communities' concerns. Therefore, the agenda, control and power in this type of consultation stay firmly with the organisation. On the higher rungs of the ladder

power begins to be shared via 'partnership' working and 'delegated power' up to the level where decision-making is handed over with 'citizen control'.

As Anderson (1996, 72) suggests 'consultation of communities is frequently at the level of offering options, listening to feedback but not allowing new ideas. [...] When professionals support independent community interests without imposing an outside agenda this encourages a greater level of citizen power'. In other words, citizen power involves the community setting the agenda.

Arnstein's model identifies the steps involved in organisations sharing power and control with external groups, and is useful in supporting the analysis of the extent to which the emancipatory research principles underpinning this study helped support the Pioneers gain access to decision-making at the Centre. In particular, Arnstein's approach is useful when considering how museums consult with communities or enter into power-sharing relationships with them. As will be discussed in Chapter 3, this resonates with the works of key authors in the museum literature who focus on issues relating to power-sharing in the co-production of exhibitions with marginalised communities (Lagerkvist 2006; Lynch 2007; 2011a; Mulhearn 2008; Lynch and Alberti 2010).

Solomon (1976, 29) also considers the agency that organisations have when engaging with empowering practices, and states that 'the success or failure of empowerment is directly related to the degree to which [the] service delivery system itself is an obstacle course or an opportunity system'. Therefore, organisational cultures have an impact on how engaged people can become in the empowering processes, an idea which will be of importance when thinking about the way that the Pioneers have engaged with the Centre.

Dalrymple and Burke (2006, 107) state that the process of empowerment 'serves to counteract the oppressions that shape and inform the lives of those who do not have access, or have limited access, to the power structures of society'. This is in-line with Croft and Beresford's views on empowerment for service users as a 'means [of] challenging their disempowerment, having more control over their lives, being able to influence others and bring about change' (2000, 116). Although Croft and Beresford's discussions relate to users of social work services, their perspective could equally apply when thinking about disabled people as service users of museums.

The final section of this chapter will explore the issues that are raised by examining the ideas involved in liberatory education. As described by Freire (1972), liberatory education has been used as a methodology to support people to empower themselves and lift themselves out of oppressive circumstances, and therefore it is important to explore what this concept might offer to this study.

### ***Liberatory Education***

Solomon (1976) places significance on the need for oppressed peoples to be supported to develop the skills needed to empower themselves, rather than social workers making the changes for them. Solomon's argument closely parallels Freire's (1972) influential publication *Pedagogy of the Oppressed*, which centres on the oppression of indigenous peoples in Brazil. Freire is widely considered to have been one of the most significant theorists in the field of education in the twentieth century (Mayo 1999). His work primarily focuses on impoverished working class people in Brazil and the wider Latin Americas

(Coben 1998; Mayo 1999). He creates a strong argument that 'liberatory education', also called 'empowerment education' (Anderson 1996), can involve a learning process which helps oppressed people to change issues for themselves, rather than relying on advocates to call for changes on their behalf.

He asks:

Who are better prepared than the oppressed to understand the terrible significance of an oppressive society? Who suffer the effects of oppression more than the oppressed? Who can better understand the necessity of liberation? They will not gain this liberation by chance but through the praxis of their quest for it, through their recognition of the necessity to fight for it (Freire 1996, 27).

Freire (1972) values the lived experience of oppressed people and calls for liberatory education, which could teach oppressed people how to free themselves from oppression and gain power within society. Although at times he states this in (quite literally) revolutionary terms, this concept can be applied to our contemporary society. Indeed, by the late-1990s Freire referred to this pedagogy more in terms of social democratisation than as a revolutionary mechanism (McLaren and Leonard 1993). Weiler (1994) applies Freire's ideas to the oppression that can affect women, black people and lesbians in her feminist critique of Freire's work. From Freire's standpoint in order to be freed from oppression, oppressed peoples need to engage in learning experiences that teach them the skills to fight against oppressive practices.

As Coben (1998) explains, Freire also asserts that education cannot be delivered from a politically neutral position, and argues that oppressed people need to 'undergo changes in their consciousness so that they understand that they are oppressed and can act to change their situation' (Coben 1998, 53). He describes his approach as involving a series of concepts that include

conscientization, praxis and dialogue (Freire 1972). Freire (1976, 19) claims that 'conscientization' (*conscientização* in Portuguese) represents 'the development of the awakening of critical awareness'. Furthermore, he describes oppressed people as being trapped in a 'culture of silence', as they are unable to articulate their views of the world, and are therefore unable to act to change their situation (Freire 1972). In their analysis of Freire's work, McLaren and Leonard (1993, pxiii) argue that: 'This process embraces a critical demystifying moment in which structures of domination are laid bare and political engagement is imperative'. Freire (1976) explains that the aim is for people to achieve the state of awareness where they are able to critically interpret the depth of their problems. He believes that there is a relationship between the knowledge of a person's reality and the work that is needed to transform it (Freire 1975). Analysing Freire's literacy programmes, Brown describes this series of concept as 'a process in which people are encouraged to analyze their reality, to become more aware of the constraints on their lives, and to take action to transform their situation' (Brown 1975, 20). Freire (1972) claims that this can be achieved through 'problem-posing education'. In his application of Freire's work, Shor (1993, 25) states that this involves the teacher posing 'problems derived from student life, social issues, academic subjects, in a mutually created dialogue'. Freire (1972) views this increased awareness as one of the aims of liberatory education, and insists that it can be achieved through the interrelated concepts of praxis and dialogue. He defines the term praxis as 'the action and reflection of men upon their world in order to transform it' (Freire 1972, 52), and considers reflection as an important learning tool that is linked to dialogue.

Freire contrasts this approach with what he names 'banking education', and states that banking education aims to transmit the dominant class's views and values in order to 'maintain the submersion of consciousness' (Freire 1972, 54). 'For Freire, the issue is disarmingly simple: the education process mirrors society as a whole, so that banking education mirrors oppressing society and dialogical, problem-solving, conscientizing education and is a characteristic of a humane society based on libertarian values' (Coben 1998, 78). Therefore, Freire's concepts focus on supporting oppressed peoples in their efforts to obtain a political awareness that forms a basis for reflecting on their situation and taking action to change it.

Freire (1972; 1976) applied these ideas within literacy programmes which were designed to bring about conscientization. When working with impoverished working class people in Brazil, he considered literacy skills to be an important first developmental step, as the majority of these people were illiterate. Although this study does not focus on a literacy programme, the concepts of conscientization, praxis and dialogue are important to the analysis of the process of undertaking emancipatory research, and will be revisited in chapters 5 and 6.

Although many authors (McLaren and Leonard 1993; Anderson 1996; Mayo 1999) regard Freire's work as seminal, it is heavily criticised by Leach (1982) Taylor (1993) and Coben (1998) as being too binary and linear. Coben (1998) points out that the world is not neatly divided into the oppressed and oppressors, but is more complex than these binary positions. However, overall, even when taking these views into account, Freire's ideas about creating pedagogy to

support people to challenge oppression and gain a voice are of central importance to this study.

## **Conclusion**

This chapter has explored the nature of social exclusion, how it is defined and how it manifests itself in people's daily lives. It focused on how social exclusion is related to social inclusion, and how oppression is more centrally linked to issues of power and powerlessness; with the work of Foucault (1990; 2005; 2006) and Lukes (2005) shaping this discussion. Foucault's (1990; 2006) work served to highlight how power is exercised through social relationships, and is exercised on a daily basis through a myriad of different social relationships.

The literature relating to empowerment was then investigated, as empowerment is seen as a key mechanism to challenge inequalities of power. This discussion drew on the work of Freire (1972) and Solomon (1976). Solomon's work explores how oppressed people can be supported to overturn the power blocks in their lives through the development of the skills needed to influence others, and Freire's (1972; 1976) work on liberatory education has been seen to be of relevance when thinking about how to support young disabled people to challenge exclusionary practices. Before turning to look at how the issues that have been raised in this chapter are relevant to museums, Chapter 2 will first focus on the context of disability. In doing so, it will aim to analyse how the overarching issues of exclusion, oppression and empowerment can apply to disabled people's place in society.

## **Chapter 2: The Conceptualisation and Re-conceptualisation of Disability**

### **Introduction**

Having established a broad base of theory and literature, this chapter explores how these overarching issues apply to the disability context, beginning with how the term disability itself is defined. It is sometimes referred to as an ‘umbrella’ term (World Health Organisation 2013), as it can encompass a wide range of issues, determining which people in society are considered disabled has evolved over time in response to changes in cultures, customs and beliefs (Oliver, Sapey, and Thomas 2012). The evolving nature of this definition is important to consider as it directly affects the ways in which disabled people are treated. The definition that is most prevalent in a society also exerts an influence over public policies and practices in relation to disability.

The chapter also examines how society has conceptualised and re-conceptualised disability over time, referring back to the overarching issues of exclusion, oppression and empowerment discussed in Chapter 1. Disability studies scholars (Oliver 1983; 1990; Thomas 1999; Swain and French 2000) have developed and vigorously debated a variety of models explaining the ways that individuals, groups and societies think about disability. This theorising has been influential not only in the shaping of academic debates, but also within the disability rights movement and on subsequent legal and policy developments. The way that disability is modelled differs between cultures and countries, however, this chapter focuses on the UK debate.

## **Defining the Term ‘Disability’: Changing Perspectives**

As noted above, the way that the term disability is understood has fundamentally changed over time. According to Oliver and Barnes (2012, 14), there is importance attached to the way that disability terminology is perceived: ‘The social world differs from the natural world in (at least) one fundamental respect: that is, human beings give meanings to objects in the social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them’. The meanings that have been attached to the word disability have been shaped by moral views, economic values, medical diagnoses and technological advancements as well as social, cultural and human rights perspectives (Oliver 1990; Barnes 1996a; Oliver, Sapey, and Thomas 2012). For example, it has been argued that the social changes that accompanied industrialisation had a significant effect on who was perceived to be disabled. Interpreting the work of Finkelstein (1980), Barnes (1997) states that in the pre-industrial era economic activity consisted primarily of agricultural or cottage-based industries, and that these forms of production did not preclude the involvement of disabled people. As described by Walsh, Stephens and Moore (2000, 222): ‘People with impairments were [...] likely to be absorbed into the family – or household – economy, where they would perform whatever tasks they could manage’. Thus, a person with an impairment was not necessarily viewed as disabled within their community.

This changed with industrialisation, as economic and social values altered within society. From the industrial era onwards, impairments became increasingly labelled and differentiated as medical knowledge about the body advanced. At the same time, ‘production processes became more specialised, and an

individual's level of skill and speed of work became important to potential employers' (Walsh, Stephens, and Moore 2000, 222). This meant that people with a range of impairments started to be excluded from the workplace. Oliver and Barnes (2012) state that the issue of definitions of disability thus became important in the industrial era as there was a need to identify and classify the growing numbers of the urban poor. As cited in Oliver and Barnes (2012), Stone (1984) asserts that disability became an important social category as it helped to distinguish people who were unable to work from those who were unwilling to work. Oliver and Barnes (2012, 14-15) explain why the way that disability is defined became important:

Throughout the twentieth century this process has become ever more sophisticated, requiring access to expert knowledge, usually residing in the ever-burgeoning medical and paramedical professions.<sup>5</sup> Hence the simple dichotomy of the nineteenth century has given way to a whole new range of definitions based upon clinical criteria or functional limitation.

The term 'functional limitation' refers to the limitations of disabled people's bodies in relation to a perceived 'normal' level of functionality, activity or movement. This is a controversial term, and has been criticised by disabled people, as it compares disabled people's bodies against what is perceived to be 'normal'. As Davis (2010, 3) contends: 'We live in a world of norms'. He explains that we constantly assess what is average and normal for our bodies from our intelligence, weight and height through to issues like our cholesterol levels. He states that:

To understand the disabled body, one must return to the concept of the norm, the normal body. So much writing about disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of color. But with recent scholarship on race,

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<sup>5</sup> The term 'paramedical' in this context refers to professions who support medical practitioners, such as physiotherapists or occupational therapists.

which has turned its attention to whiteness, I would like to focus not so much on the construction of disability as on the construction of normalcy (2010, 3).

He indicates that the concept of the normal body only came into common usage in the UK around 1840 with the advent of industrialisation. With advances in medical sciences and the development of the field of statistics, bodies began to be measured against one another in order to assess averages within populations, and therefore determine what was perceived to diverge from the norm. This led to the labelling of certain bodies as 'abnormal' or 'deviant' when set against established 'norms' and 'ideals' (Davis 2010).

Davis's ideas on normalcy have parallels with Kumari Campbell (2001; 2008; 2009) whose work focuses on the concept of 'ableism'. She states that 'from the moment a child is born she/he emerges into a world where she/he receives messages that to be disabled is to be less than, a world where disability may be tolerated but in the final instance is inherently negative' (Kumari Campbell 2008, 151). Within this evolving context, deviation from the normal is therefore seen as undesirable. Set against the term 'disablism', which Kumari Campbell (2008) defines as the social construction of disability and its negative effect on disabled people, she states that ableism is:

a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human (2001, 44).

As can be seen from Oliver and Barnes (2012), Reeve (2002; 2004) and Kumari Campbell (2001; 2008; 2009), the labelling and medicalisation of impairments can have a significant impact on disabled people's lives. In Watson's (2002) study 'Well, I Know this is Going to Sound Very Strange to You, but I Don't See

Myself as a Disabled Person', the majority of respondents saw themselves as 'normal people' who happened to have an impairment. Their self identity was not fundamentally based on their impairment, and was far more complex than the binary distinction between disabled and non-disabled.

As described by Oliver and Barnes (2012), from the 1960s onwards the meaning of the term disability, and the language used in relation to it, began to be challenged by the emerging UK disability movement. This social movement was formed in the wake of what Oliver (1990, 3) calls 'the politics of minority groups', where groups that were affected by particular social problems realised that in order to effect change they needed to redefine the issues. Oliver elaborates:

Thus a number of groups including women, black people and homosexuals, set about challenging the prevailing definitions [...] by attacking sexist and racist biases in the language. They did this by creating, substituting or taking over terminology to provide more positive imagery (e.g. gay is good, black is beautiful etc.) (1990, 3).

From the late-1960s onwards, disabled people started to join together to lobby for their rights and began to taking ownership of the language and definitions used to describe disability (Oliver 1990; Barnes and Mercer 2003). For example, Oliver (1990) discusses how disabled people started to question the use of offensive words like 'cripple' and 'mongol', and depersonalising terms such as 'the handicapped' and 'the blind'. As the UK disability movement began to gain a voice, key figures (Hunt 1966; Union of Physically Impaired People Against Segregation [UPIAS] 1976; Finkelstein 1980; Oliver 1981; Oliver 1983; Oliver 1990) outlined the argument that society had failed to recognise and accommodate the needs of people with different impairments, and that they were affected by prejudice. In 1976, the first definition of disability crafted by

disabled people was articulated as: 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activity' (UPIAS 1976, 14). This was an important development, as it went beyond describing disability in terms of medical issues. Disabled people's impairments were still central to the definition, but crucially for the first time the exclusion of disabled people from society was introduced. The definition initially identified only people with physical impairments, as the members of the groups were people with physical impairments, who felt that they could not legitimately talk on behalf of other people with different impairments. However, 'subsequently the restriction to "physical impairments" was dropped to incorporate all impairments – physical, sensory and cognitive' (Oliver and Barnes 2012, 21). The Disabled People's International's (DPI) 1982 definition then went a stage further in the separation of impairment from its consequences within society:

- Impairment: is the functional limitation within the individual caused by physical, mental or sensory impairment.
- Disability: is 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 or social barriers.

This emphasis on the physical and social barriers decoupled the term impairment from the disabling effects within society. For example, a person with a physical impairment may need to use a wheelchair. However, viewed from this perspective it is not their impairment which disables them but the way that society has been organised, and which does not take account of their needs. If

the physical environment incorporates features such level access, ramps and lifts, a person with an impairment is not disabled by the organisation of society. If disability is seen as a social construction, it is then viewed in terms of the socio-economic, cultural and political disadvantages that results in the exclusion of people with impairments. This perspective will then translate into social policy which focuses on tackling disabling barriers to facilitate people with impairments' inclusion.

Although the DPI's (1982) definition was developed 30 years ago, Oliver and Barnes assert that 'the dominant meanings attached to "disability" in most western industrial and post-industrial societies remains firmly rooted in personal tragedy' (2012, 11), and that it is still primarily regarded as a health issue. They explain that there are a number of reasons why the way that disability is defined is important, as will be outlined in the next section. If it is viewed through the lens of personal tragedy, then disabled people will be viewed as 'the victims of some tragic happening or circumstance' and that this treatment 'will occur not just in everyday interactions but will also be translated into social policies' (Oliver and Barnes 2012, 14). Therefore, it appears that further implementation of disabled people's definitions is needed before they are more commonly understood and accepted. Oliver, Sapey and Thomas (2012, 11) expand on why definitions are important, citing Townsend (1979), who suggests that 'professional definitions [of disability] can be divided into five broad categories: abnormality and loss, clinical conditions, functional limitations, deviance and disadvantage'. Townsend describes these categories as follows:

- Abnormality and loss: anatomical, physical or psychological loss, in other words loss of a limb or a sense such as sight leading to blindness.

- Clinical conditions: conditions that alter or interrupt physical or psychological processes, in other words conditions such as multiple sclerosis or schizophrenia.
- Functional limitations: conditions that restrict or prevent people from performing 'normal' personal or social tasks. For example, an amputation.
- Deviance: people whose behaviour deviates from the 'norm', such as people with learning impairments or mental health issues.
- Disadvantage: defines disabled people as being treated in a disadvantageous way within society.

All of these ways of defining disabled people cast their lives in a negative light, and this may go some way to explaining why the personal tragedy perspective of disability still predominates within society, as suggested by Oliver and Barnes (2012). As an alternative to this personal tragedy perspective, Oliver and Barnes state that:

it logically follows that if disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals (2012, 14).

The issue of disability as a form of social oppression will be explored later in the chapter, and Goodley (1997, 372) succinctly describes this standpoint: 'Disabled people are just that, people disabled by a social, economic, cultural and political contemporary climate'. As previously discussed, Oliver (1990) argues that disabled people have been denied access to key political, educational and cultural institutions that could enable them to fully participate in society, and that this exclusion has resulted in their marginalisation. This allows this argument to

be firmly situated in the realm of museum's responsibilities as will be discussed in Chapter 3.

### ***Types of Impairments and their Position against the 'Normal'***

Within the debates about the social model of disability, which will be discussed later in the chapter, it has been argued that the daily realities of living with an impairment have been 'played down' in favour of the political agenda relating to highlighting society's responsibilities (Morris, 1991a; Crow, 1992, 1996; Shakespeare, 1992; Thomas, 2007). Therefore, before moving on to look at how disability is conceptualised through the models of disability, it is important to be clear what is meant by the term impairment, which incorporates a range of people with physical, sensory, intellectual, health and mental impairments (Barnes 1996a; Oliver, Sapey, and Thomas 2012). Thus:

- Physical impairments: people who have physical bodily issues such as people who are affected by spinal injuries or club feet.
- Sensory impairments: people who are Deaf<sup>6</sup> or have a hearing impairment, or people who are blind or have a visual impairment.
- Chronic illness or health issues: people who have health conditions that limit their life opportunities, for example, people with muscular dystrophy or who are affected by chronic pain.
- Learning or developmental impairments: people with mild, moderate and severe cognitive or developmental impairments, for example, people with Down's Syndrome or autism.

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<sup>6</sup> As will be discussed in more detail in the next section, the word Deaf has a capital D, as in the UK '[D]eaf people, on the whole, want to be recognised as a cultural-linguistic minority. They do not always identify themselves as disabled or as part of the disabled community' (Dodd et al. 2006, i).

- Mental health issues: people who are affected by mental distress, such as people with depression or schizophrenia.

Due to the interplay between people's impairments and the physical and social world, the extent to which a person is disabled will vary from individual to individual as a result of the complex nature of this interaction. The degree to which the person also identifies with their impairment or the disabling interaction with society, as described by Watson (2002), will also vary. Impairments and disabilities are more complex than the binary position of disabled and non-disabled which predominates within society (Druckert 1998; Shakespeare and Watson 2001), as many impairments can be seen to be on a continuum (Shakespeare and Watson 2001). For example, people who are affected by depression can experience mild through to severe symptoms. The diagnosis of depression can be complex, as it can be seen as a range of overlapping conditions that include anxiety disorders, mild and major depression (Angst and Dobler-Mikola 1985; Haddad and Gunn 2011), with the condition not necessarily limiting the person's opportunities in life. Additionally, conditions like depression are not fixed, as the person can improve and/or relapse over time (Haddad and Gunn 2011). The point at which a person's impairment significantly affects their life, and when the physical and social world causes a disabling effect can be complex to identify.

One final issue to consider before moving on to look at how disability is conceptualised through the models of disability is whether disabled individuals feel that they identify with or belong to a collective 'disability community'. As previously discussed, in Watson's (2002) paper the majority of the people interviewed did not identify themselves as a disabled person. They saw

themselves as people with impairments who were getting on with their lives. Indeed, Watson suggests that disabled people do not have a common group identity. However, Watson (2002) and Barnes and Mercer (2003) discuss how the sense of a disability community can take form around people who have the same type of impairment, as to some extent they have a common embodied life experiences. Padden (2002) explains that this sense of community is particularly strong within the Deaf community. He explains that the children of Deaf parents are born into a culture and language (British Sign Language) that they acquire from birth, and that they also learn the beliefs and behaviours of their parents' cultural group.

However, in terms of a collective community, Deal's (2003) research shows that people across the umbrella term 'disability' do not necessarily want to associate with people with impairments that are different from their own. For example, he explains that physically impaired people who are wheelchair users do not always want to be associated with people with learning impairments, as people often assume that they have a learning impairment and therefore, use inappropriately simplistic language when speaking with them. He states that there are a variety of complex reasons which mean that disabled people disassociate themselves from other impairment groups, which include stigma and the need to compete for the scarce allocation of funding and resources. Watson (2002, 525) summarises this issue by stating that disabled people do not:

share a common religion, common political beliefs, a common social class. There are differences along the lines of gender, age, ethnicity, sexuality, region, partnerships and health. All these serve to challenge the idea of a unanimity of a disability collective. [...] Whilst it could be argued that all disabled people share one essential characteristic; that is they have an impairment, the idea of a common identity based on the presence of that impairment, compelling as it may be, is not sustainable.

There is one area within the literature, however, where disabled people are talked about in terms of a unified community. Finkelstein (1993) and Oliver (1996) state the need for a unified movement to give disabled people a strong political voice in order to fight for their fundamental rights, and for legislation to protect disabled people against discrimination. Shakespeare (2006a) describes this as a shared political identity.

However, authors such as Morris (1991b), Crow (1996) and Fawcett (2000) view this undifferentiated unified grouping as problematic, as people with impairments come from different gender, age, race, ethnicity and impairment backgrounds. Therefore, the term 'disability community' is highly contested within the disability literature with no common consensus on its definition, or indeed whether it actually exists. For the purposes of this thesis a group or collective identity for disabled people simply means people with impairments who share a common experience of oppression within UK society.

Within this backdrop of challenges to the way that society thinks about disability, the UK disability movement and the growing field of disability studies began to challenge the way that society thinks about disability through the development of the social model of disability. This model was constructed to challenge society to take responsibility for the physical and social barriers that prevent people with impairments from fully participating in society. In order to place this model in context, it will be contrasted against the medical model, which can be used to explain many peoples' current perceptions of disability.

## **The Models of Disability**

As discussed by Llewellyn and Hogan (2000) and Finkelstein (2004), conceptual models are artificial constructions. However, they are designed to explain issues that are multi-dimensional and abstract in nature, and so allow us to gain insights into complex situations what we might not otherwise fully understand. A series of such models were developed from within the disability movement to explain the changing ways that people have thought about this issue. As discussed by Oliver (2004) and Wilder (2006), within every society there are competing models of disability, with some models gaining popularity at different times in society's development. French and Swain (2002) assert that the models put forward by powerful groups in society tend to dominate over less powerful groups' perceptions. For example, medical professionals' conceptualisation of disability tends to dominate over the models developed by disabled people. Oliver (1993, 4) explains the consequences of this for disabled people, suggesting that the "lack of fit" between able-bodied and disabled people's definitions is more than just a semantic quibble for it has important implications both for the provision of services and the ability to control one's life'. Individuals' perceptions of and attitudes towards disability will be shaped by many factors including influences from their family, peers and the media. The way in which a person views disability will then affect their thoughts about and actions towards disabled people, and the way that they respond to them in their daily interactions. For example, people who have a faith might be particularly influenced by religious texts, and perhaps think about disability in terms of a religious burden. People's attitudes will also influence the more formal creation and delivery of services, policies and practices.

Over time, there have been a range of ways in which people have understood disability, and the UK disability movement has developed a series of models intended to explain these different viewpoints. The main models can be described as the religious model, the medical model (sometimes known as the individual model), the personal tragedy model (sometimes known as the charity model), the social model and the affirmation model. The main two models that will be explored in this chapter are the medical model and social model, as these are the models that are currently competing for predominance in our contemporary society. The religious model and the personal tragedy (or charity) models will not be explored in detail, as although they can be important to explain some people's conceptualisation of disability, they did not underpin staff thinking at the Holocaust Centre, and therefore do not form part of the analysis of the data collected.

However, to give a brief context to these two models, religious thinking about disability occurs in many societies and throughout history. In the present day, it predominates in cultures in which attitudes to disability are linked to ignorance, fear and prejudice (Oliver 1990; Barnes 1997; Davis 2010) and arise out of superstition and a lack of medical knowledge (Oliver 1990). The religious model can be used to explain people's perspective on disability if they are particularly influenced by religious teachings. For example, disability can be viewed as a consequence of sin or as a religious burden (Barnes 1997; Stiker 1997; Oliver, Sapey, and Thomas 2012). The personal tragedy (or charity) model can be at the forefront of people's minds if they consider disability to be a tragic event in disabled people's lives. As described by Swain, French and Cameron (2003), this model assumes that impairment and disability are about loss, and that

disabled people are to be viewed with pity. Both the religious and personal tragedy models view disability in a negative light. Conversely, the affirmation model views disability from a positive standpoint. This model will be explored towards the end of this chapter, as it is important when considering how the Pioneers' perceptions of themselves changed through their involvement in the research. The next part of the chapter will explore the medical model, which was developed to explain the changes that occurred in UK society post-industrialisation, before moving on to look at the social model.

### ***The Medical Model of Disability***

The way that disability was viewed within society evolved with the rise of industrialisation and the growth in urbanisation from the eighteenth century onwards (Barnes 1997; Barnes, Mercer, and Shakespeare 2003). Machinery in the new factories required workers with manual dexterity, and a mode of work developed that centred on regimented working patterns and high production demands, presenting difficulties for people with a range of impairments (Barnes, Mercer, and Shakespeare 2003). Oliver (1990) draws on Marxist analysis to explain how disabled people came to be viewed as a burden on society, as they were unable to take on heavy physical labour, disabled people were deemed unable to contribute to the economy. This sense of disabled people as an economic burden was coupled with an increased emphasis on the importance of 'scientific rationality', medical knowledge and social progression (Oliver 1990; Barnes 1997; Barnes, Mercer, and Shakespeare 2003). As set out by Barnes, Mercer and Shakespeare (2003, 19):

The rise of the scientific medical profession [...] and its success in medicalizing illness and impairment gave legitimacy to radical shifts in the treatment of disabled people. [...] An increasing range of techniques was introduced to identify, classify, and regulate sick and disabled people. This heralded the 'therapeutic state' with its novel and polarized concept of normal and abnormal, sane and insane, healthy and sick.

This medicalised perspective, framing disabled people as a burden is still common in society today, and this way of thinking about disability assumes that it is an intrinsic characteristic of an individual, arising from bodily or mental impairments (Hahn 1986). Sometimes called the 'individual model of disability' (Oliver 1990; Barnes, Mercer, and Shakespeare 2003; French and Swain 2012), it positions disability as the individual's problem. From this perspective the difficulties that disabled people experience are caused by the individual's impairment(s) or condition(s). Oliver (1996) describes these as functional limitations or psychological losses, and asserts that such beliefs are linked to the perception that disability is intrinsically connected with illness. Following this approach, if a person walks with callipers, the problems that they may have in accessing buildings with steps are due to their bodily limitations. As Hahn (1986, 131) notes the medical model 'imposes a presumption of biological or psychological inferiority upon disabled persons'. If disabled people's bodies and minds are seen as 'ill', 'defective' or 'abnormal', the focus of medical practitioners will be on diagnosis, treatment, cure and rehabilitation, with a view to supporting the disabled person to 'fit into society'. As Oliver, Sapey and Thomas (2012, 12) state: 'there is likely to be a programme of re-ablement designed to return the individual to as near a normal a state as possible'. With the rise of industrialisation, the concept of 'able-bodied' normality became the benchmark by which people with impairments were judged (Oliver 1990). The implication of this way of thinking is that if the problem resides within the

individual, then it is the individual's responsibility to cope with the effects of their impairment. From this perspective, society is not required to support the disabled person's needs, as the onus is on the disabled person to 'fit' into society.

### ***Criticisms of the Medical Model***

As Oliver (1990) and Brisenden (2003) both suggest, this medicalised way of thinking about disability places an 'undue emphasis on clinical diagnosis' (Oliver 1990, 48). Oliver agrees that medical support is entirely appropriate when it relates to the diagnosis of impairments, stabilisation of medical conditions and treatment of illnesses. However, he explains that this perspective also frames disabled people's lives in medical terms, despite their lives being more than a collection of medical 'facts' (Oliver 1990). The limitations of this model have also been passed on to other sectors, leading to community-based services (and many other sectors) adopting an overly clinical preoccupation with disability (Oliver 1990; Barnes, Mercer, and Shakespeare 2003; Brisenden 2003). Framing disabled people's lives in medical terms cannot support a more holistic understanding of their lives (Brisenden 2003).

Issues of power and control can also arise in disabled people's conversations with medical practitioners, who are placed in the position of the 'expert' as they hold the 'authorised' expertise about specific medical conditions. At the centre of this model can be an unequal relationship if the disabled person's embodied knowledge is not valued alongside the medical practitioner's views. Disabled people may have a difficult time navigating relationships with medical professionals, on the one hand they may need support and treatment related to

their impairments, but on the other they may not feel that their views are being listened to in relation to decisions that are being made about their lives. In Chapter 1 we saw these issues of power relationships described in broader terms by Wallerstein (1992), Lukes (2005) and Foucault (2006). In this context this type of unequal power relationship can leave disabled people feeling powerless; it therefore frames disability within discourses on oppression. The issue of disability as a form of social oppression will be discussed later in this chapter.

A further criticism of the medical model focuses on how it ignores the role that social and environmental issues have on the disabling process (Oliver 1990). As will be discussed later in this chapter, the significant social, physical, attitudinal and institutional barriers that disabled people face in society will still remain post medical diagnoses. With regards to this study, if museum staff view disability in accordance with the medical model they will primarily focus on the 'problems' that the disabled person has when accessing their services due to their impairment. Therefore, the museum's responsibility in relation to barriers that might prevent disabled people from accessing their buildings and services would not be at the forefront of their thinking.

### ***The Social Model of Disability***

Initially developed by Oliver the social model emerges from his encounter with the 'Fundamental Principles' document (UPIAS 1976) and the way it forced him to rethink his own experiences of impairment and disability (Oliver 2009). He further explains that it 'turned the understanding of disability completely on its head by arguing that it was not impairment that was the main cause of the social

exclusion of disabled people but the way society responded to people with impairments' (2009, 43). Barnes (2003b) describes how Oliver's conceptualisation of disability stemmed from his attempts to explain his insights when training social workers and in delivering disability equality training.

As described by Oliver, Sapey and Thomas (2012, 16), 'when using this social model of disability the term "disabled people" means people with impairments who are disabled by society'. They expand on this issue by comparing the individual and social models:

In short, the individual model focuses on the functional limitations of individuals in attempting to use their own environment. The social model, however, sees disability as being created by the way the social world, for example employment, housing, leisure and health facilities, are unsuitable to the needs of particular individuals (2012, 16).

This statement is important as it describes the way that society 'disables' people with impairments. It places disability issues within the human rights discourse, and asserts that disabled people are disadvantaged by a world designed to suit the needs of non-disabled people. Within the literature, disabled people describe how important the creation of the social model has been to their understanding of disability. For example, Crow (1996, 56), a disabled activist, artist and filmmaker explains:

My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.

As described by Thomas (2002, 40), 'when disabled individuals encounter the social model, the effect is often revelatory and liberatory, enabling them, perhaps for the first time, to recognize most of their difficulty as socially caused'.

She goes on to state that the social modellers' idea is that 'disability is the outcome of social arrangements that work to restrict the activities of people with impairments through the erection of social barriers' (2002, 40). She describes how this idea enables disabled people to begin to identify disabling barriers in all areas of their life. According to Oliver (1996), Oliver, Sapey and Thomas (2012) and Thomas (2002), these areas can include employment, housing, leisure, culture, health, education, transport, welfare services and civil and political rights. This is in accord with Fawcett (2000), French (2004) and French and Swain (2012), who state that the social model is often referred to as the 'barriers approach'. French and Swain (2012) assert that environmental, structural and attitudinal barriers can impinge upon the lives of disabled people, impeding their inclusion within society. They describe these barriers in the following ways:

- Environmental barriers – refer to physical, sensory and intellectual barriers within the environment. For example, steps into buildings or a lack of Braille or sign language interpreters.
- Structural barriers – refer to the underlying 'norms' and cultures within organisations which do not take account of disabled people's needs. For example, policies and working practices that do not take account of issues like fatigue or pain in working environments.
- Attitudinal barriers – refer to negative attitudes and behaviours towards disabled people.

These have broadly been called 'socio-structural barriers'. French and Swain argue that these barriers can interact 'to give rise to economic, political and cultural disadvantage at every level in society' (2012, 7). They elaborate further:

It can be seen that the social model of disability locates disability not within the individual disabled person, but within society. Thus the person who uses a wheelchair is not disabled by paralysis but by building design, lack of lifts, rigid work practices, and the attitudes and behaviour of others. Similarly, the visually impaired person is not disabled by lack of sight, but by lack of Braille and large print, cluttered pavements, and stereotypical ideas about blindness (2012, 7).

Some barriers, such as steps that can block wheelchair users, are easy to identify. However, others are less visible and concrete, such as prejudice against disabled people. Attitudinal barriers can be the most complex and difficult to address, and often disabled people have to deal with many barriers at the same time. For example, a blind person going to a meeting may be faced with an inaccessible building, may not be given accessible information, and may not be allocated the help needed to find the meeting room. Additionally, disabled people not only have to deal with barriers that exist now, but also with barriers that have prevented their progress in the past. For example, a disabled person who did not go to a mainstream school may not have acquired the qualifications needed to enter into employment. This issue links to the ideas put forward by Solomon (1976) in relation to power blocks that prevent oppressed people's progress in life. According to Oliver, Sapey and Thomas (2012, 19) 'the overriding importance of the social model of disability is that it does not locate the problem of disability with disabled people because they have "something wrong with them" – it rejects the individual pathology model'. This way of thinking about disability places the onus and responsibility on society to dismantle disabling barriers that affect people with impairments, and also provides disabled people with a central rallying point around which to campaign for change.

## ***Criticisms of the Social Model***

Although the social model was developed from within the UK disability movement and the field of disability studies, Barnes (2000, 443) notes that 'despite the success, or perhaps because of it, the social model is not without its detractors'. Key authors (Morris 1991a; Crow 1992; 1996; Shakespeare 1996a) have been vocal in questioning whether this model is able to fully encapsulate the experiences of all disabled people. As will be discussed, these critiques centre on issues of impairment, the body and bodily pain, feminist and multicultural perspectives, and also whether the model has taken account of the psycho-emotional effects of disability. Barnes (1997, 10-11) states that these critiques call for a renewal of the social model 'to include the diversity of experience within the disability community'. He describes how, in the 1990s, a second generation of disability writers began to challenge the prevailing views of the social model (Barnes 1997). This heated debate has now been raging for over 20 years and Thomas (2004b, 572-3) argues that the social model 'has become the principal point of reference in disability studies debates in Britain. [...] The model now has an almost iconic status, and whether authors are for or against it their writings are almost invariably in dialogue with it'. Hence, it is clear that the social model has an enduring influence on disability activists and the field of disability studies.

The critiques centre on whether the social model is able to take adequate account of different aspects of people's experiences and can broadly be divided into two categories: critiques where the main focus is on whether a particular issue is given enough prominence within the model, and critiques where an important issue has been overlooked.

### *Critiques about the Prominence of Key Issues*

The first criticism that has been levelled at the social model is that it has not taken adequate account of disabled people's impairments (Morris 1991b; Crow 1992; 1996; Thomas 2007; Hughes 2009; French and Swain 2012). Morris asserts that the social model 'denies the embodied experiences of pain and affliction which are integral to the lives of many people with impairments' (Morris 1991b, 335), while Shakespeare insists that to 'mention biology, to admit pain, to confront our impairments [...] has been to risk the oppressors seizing on evidence that disability is really about physical limitation after all' (1992, 40). This echoes Crow's (1996) critique questioning why impairments are 'played down' within social model discourses. Crow calls for the everyday reality of living with an impairment to be more fully discussed, insisting that: 'many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness' (Crow 1996, 209).

This leads on to feminist critiques of the social model that centre on whether disabled women's perspectives have been given adequate prominence within broader discourses about disability. For example, French and Swain (2012, 8) comment that 'Wendell (1997) draws parallels between the oppression of women and the oppression of disabled people, which is built around attitudes towards the body in patriarchal society'. Indeed, Wendell (1997) argues that our contemporary society has an obsession with idealising the body. She argues that in societies that value fit and healthy bodies, people with physical impairments are marginalised. Furthermore, disabled women are more likely to be affected by these attitudes, as women are judged by their bodies to a greater extent than men.

The feminist critiques of the social model are echoed in calls for the social model to more fully represent people who are affected by multiple forms of oppression. For example, Stuart (1994) asserts that the social model produces an exclusive analysis that overlooks the multiple oppressions that can affect black disabled people. Stuart (1993), Vernon (1996; 2002) and Banton and Singh (2004) similarly look at issues of race and whether it has adequately been explored in terms of disability. This led Oliver, Sapey and Thomas (2012, 18) to critique the social model and state:

The use of the social model of disability needs to ensure that an ethnically diverse and multi-cultural and multi-faith approach is taken, in order to incorporate an understanding of these differing perceptions of disability if it is to provide an analysis that is inclusive.

This can be taken further as the perspective of the LGBT community is largely overlooked in social model critiques. This has begun to be addressed within the wider disability literature where there is a growing body of work that explores the intersection between LGBT and disability identities (Carol 1989; O'Toole et al. 1996; Shakespeare 1996a; 1998; 2003; Butler 1999). However, social model discourses to date have not highlighted LGBT issues.

Overall, when analysing the focus of these critiques, the emphasis is not on whether the social model can represent issues of impairment, gender and multiple forms of oppression; they actually centre on whether these issues are given adequate prominence within social model debates.

### *Critiques Relating to Overlooked Issues*

One final critique of the model seems to have greater validity, as it focuses on an important aspect that appears to have been overlooked in the

conceptualisation of the social model. As has been seen in the previous section, application of the social model often focuses on the socio-structural barriers (structural, environmental and attitudinal barriers) that need to be dismantled, and the role of society in disabling people with impairments (Thomas 2002; French and Swain 2012; Oliver, Sapey, and Thomas 2012). Indeed, as previously stated, Fawcett (2000), French (2004) and French and Swain (2012) show that the social model is often referred to as the 'barriers approach'. Thomas (1999; 2004a; 2004b) and Reeve (2002; 2004) challenge this approach calling for an understanding of the role of psycho-emotional effects of disability on disabled people's lives. They both explore how the psycho-emotional effects of disability are played out through social relationships. Reeve (2004) argues that there are three causes of psycho-emotional issues for disabled people. The first of these are the psychological effects of being excluded from physical environments. This may affect people with mental health issues and learning impairments whose behaviour in public is perceived as unacceptable, and also affect people with sensory and physical impairments who are unable to navigate or even access the built environment.

She outlines the second cause by going on to say that 'in addition to the daily battle with disabling physical barriers, disabled people also have to deal with the reactions of others within society. Many disabled people with visible impairments have to deal with the frank curiosity of other people' (Reeve, 2004, 88). This 'frank curiosity' refers to the way people can stare at disabled people, and also ask inappropriately personal questions about their impairments. To explain the importance of the psycho-emotional effects of exclusion, Reeve cites Shakespeare, Gillespie-Sells and Davies (1996, 42-43), who state that 'dealing

with anger, self-loathing, and daily experiences of rejection and humiliation are amongst the hardest aspects of being a disabled person', which explains the damaging effect that the prejudice can have on disabled people's well-being.

The third internalisation of oppression that Reeve discusses concerns the way that disabled people can internalise the negative messages that they receive about disability which are prevalent within our society. She draws on the work of Morris (1991a) to discuss how negative stereotypes and prejudice can affect disabled people on a subconscious level. The internalisation of prejudice can cause low self-esteem, which can have far-reaching effects on their lives.

Barnes (1992b) explores how a lack of positive disabled role models means that disabled people are affected by negative stereotypes within media and film imagery. As stated by Thomas (1999), negative interactions with family, friends, professionals and strangers can cause disabled people to internally process oppressive ideas. This discourse echoes the work of Solomon (1976) (discussed in Chapter 1) in relation to the internalised oppression experienced by black people and how this can limit their aspirations and opportunities.

Reeve (2002; 2004) argues that social model discourses have focused entirely on socio-structural barriers, and that the remit needs to widen to include the psycho-emotional effects of oppression. She builds on the social relational model of disability, as developed by Thomas (1999; 2004a), which calls for the inclusion of structural and psycho-emotional dimensions of disability within one model. Her social relational model calls for an extension of the social model, and as Reeve (2002) argues if all other barriers were removed, issues of internalised oppression would still hold some disabled people back from leading fulfilling lives, due to damage to their psychological well-being. As all major descriptions

of the model overlook psycho-emotional issues, this critique seems to have a valid basis.

### ***Concluding Points about the Social Model***

As the social model has caused so much debate within the UK field of disability studies, it has led some academics to state that too much time has been given to discussions about the nuances of the model, rather than focusing on how to implement it (Finkelstein, 2001; Oliver, 2009). However, Goodley (1997) gives a tangible example of the benefits of the development of the social model when it is adopted within wider society. He discusses the empowering voice that social model perspectives can give to people with learning impairments, for example, and how they can aid the promotion of self-advocacy by placing an onus on service providers to take disabled people's needs into account. The promotion of self-advocacy, where disabled people advocate for their own needs rather than service providers making changes on their behalf, is seen as an important step forward. Goodley (1997, 373) claims that the focus

is shifting away from a focus on what people cannot do to what people can do. Consequently, the social model invites the promotion of self-empowerment and the inclusion of self-advocacy. [...] The self-determination of disabled people is a pivotal point of the social model [and] is intertwined with the notions of emancipatory theory, research and action.

The issues of emancipatory theory, research and action were developed as a direct consequence of disabled academics reflecting on the implications of the social model for research practices, and the need for disabled people to be empowered by their involvement in research. These issues will be explored in Chapter 4, as they underpin this study.

Drawing on Hasler (1993), Goodley (2011) argues that the social model was, and remains, the 'big idea' of the UK disabled people's movement, and overall the social model has an enduring and central influence on the disability literature. In terms of this study it has been adopted as the theoretical basis of the research, as it can be applied to the study's cultural context, and Chapter 3 will discuss museums' responsibility to ensure that disabled people can access their buildings, facilities and services.

When considering the implications of debates around the social model on this issue, the importance of the Pioneers' impairments should not be overlooked in respect to how the way that the research is planned, implemented and analysed. The issue of the psycho-emotional effects of disability are also considered in the study, as matters of low self-esteem and low self-confidence may also affect the Pioneers' involvement. Therefore, the debates around the definition and re-conceptualisation of disability have been an important influence on the study, particularly in terms of the social model as it is central to the choice of research methodology.

Before moving on to the museum context, the final matter to explore in this chapter is how the social model can be applied to issues of exclusion, oppression and empowerment.

## **Disability as a Form of Social Exclusion**

Although there is much debate about how disability is defined and conceptualised, the disability literature is unequivocal about the way that disabled people are excluded from our contemporary society. Goodley (2011, 8-

9) states this very directly, saying that: 'Disability is understood as an act of exclusion: people are disabled by contemporary society'. As explained by French and Swain (2012, 147) 'disabled people are likely to experience social isolation and discrimination because the barriers within society (environmental, attitudinal and structural) make it difficult or impossible for them to participate as full citizens'. Thomas (1999) views disability as being rooted in unequal social relationships, and draws parallels with heterosexism, sexism and racism. Howard (1999, 7) notes: 'of all the disadvantaged groups in society, the disabled are the most socially excluded'. Indeed, as discussed in Chapter 1, when Lenoir developed the term 'social exclusion' in France in 1974, one of the key groups that he identified as *les exclus* were disabled people (Morgan et al. 2007). More recent literature points to an ongoing trend of disabled people being consistently excluded within society. For example, Crowther (2007, 791) asserts that 'many disabled people and their families remain among the most socially and economically disadvantaged citizens in Britain'. Many authors (Hughes and Paterson 1997; Oliver and Barnes 1998; Thomas 2002; Roulstone and Barnes 2005) discuss the areas of life from which disabled people can be excluded. They assert that exclusionary barriers exist in the realms of housing, education, employment, transport, the built environment, cultural and leisure activities, health and welfare services and civil and political rights. However, as will be discussed in the next section, not all disabled people are excluded, due to the complex interactions between an individual and the factors that can cause exclusion. Nevertheless, social exclusion can be a very real problem for disabled people, and it is an important issue which runs through the disability literature.

## **Disability as a Form of Oppression**

As described by Oliver (1986), there is a growing body of literature which has re-conceptualised disability as a sophisticated form of oppression. Thomas (1999, 40) states that 'disability becomes a particular form of unequal social relationship which manifests itself through exclusionary and oppressive practices – disablism – at the interpersonal, organizational, cultural and socio-structural levels'. As explored in Chapter 1, her argument echoes McNay's (1992) and Clifford's (1998) assessment of the broader issues of unequal power relationships that occur within society. In parallel with Thomas's (1999) views on exclusion, Barnes (1991; 2003b) places disability oppression on a par with sexism, heterosexism and racism, an important step given that disability oppression was largely overlooked in the wider literature, as explored in Chapter 1. Barnes and Mercer (2003, 20) also examine the specifics of disability oppression, or disablism, stating that it is a specific form of social oppression which 'stems from the subordination of people because of their impairment'. This is significant given that it accords with the social model which frames this form of oppression as socially constructed. Similarly, many authors (Thomas 1999; Barnes and Mercer 2004; Barnes, Mercer, and Shakespeare 2003) utilise the work of Foucault (1967; 1973; 1977; 1979; 2006) to argue that the impaired body is a site of oppression. As Abberley (1997, 173) asserts, the disabled body is 'the site of oppression, both in form, and in what is done with it'. This reflects society's prejudices about disabled bodies, and the negative way in which disabled people are treated as a consequence of this perception.

Thomas (1999, 60) has a simple yet effective way of describing this oppression, stating that 'disability is about both "barriers to doing" and "barriers to being"'.

'Barriers to doing' relates to barriers in the physical environment which prevent disabled people's inclusion; and 'barriers to being' refers to the oppression that disabled people face in society due to their impaired bodies. This statement is important as it explains in simple language the difference between the oppression that disabled people experience and the oppression that other groups (such as women, black people and the LGBT community) face. For women, black people and the LGBT community, oppression is focused on their bodies (and, in the case of the LGBT community, their sexual orientation). Disabled people have an extra layer of barriers in addition to the oppression associated with prejudices about their bodies, as there are obstructions that can prevent them from interacting with the world around them. This illustrates the multiple levels of oppression and exclusion that disabled people can experience.

Swain and French (2000) and Charlton (2010) further complicate this issue by challenging the rigid dichotomies between of non-disabled/disabled and oppressors/oppressed. Shakespeare and Watson (2001) elaborate, stating that such divisions cannot be made on the grounds of impairment, as many impairments are on a continuum of severity that ultimately merges with the (perceived) normative state. Swain and French (2000, 570) state that 'non-disabled people can be oppressed through poverty, racism, sexism and sexual preference, as are many disabled people. Furthermore, oppressed people can also be oppressors'. For example, disabled people can be homophobic.

Wallerstein and Bernstein (1994) agree, making the case that the position of oppressor and oppressed was not a clear cut binary issue (as discussed in Chapter 1).

In the context of disability, Charlton (2010, 153) usefully reiterates many of the issues (also outlined in Chapter 1) in relation to oppression and power. He states that:

Oppression is a phenomenon of power in which relations between people and between groups are experienced in terms of domination and subordination, superiority and inferiority. At the center of this phenomenon is control. Those with power control; those without power lack control.

Therefore, he picks up on the central strands that run through the discussion so far about the relational and positional nature of power, the converse position of powerlessness and the issues of dominance and control. An analysis of Charlton's (2010) writing shows that he agrees with Foucault's (2006) ideas on power relationships, and it can be argued that Foucault has had the most widespread influence on disability discourses about such relationships, particularly when authors discuss the subordination of the disabled body (Oliver 1990; 1996; Abberley 2002; Mercer 2002; Barnes and Mercer 2004). Barnes and Mercer (2003) discuss how unequal power distributions in relationships cause deep injustices for disabled people, and how powerlessness can lead to disabled people having little control over, or choice in, their lives. They link this to issues of power and authority, in particular with professionals who are in the position of making decisions about disabled people's lives, such as medical professionals and social workers. They go on to claim that oppression is entrenched in our society, as evidenced by the highly unequal distribution of material resources, uneven power relations and lack of opportunities to participate in everyday life in comparison with non-disabled people.

Therefore, the broad issues of oppression, power and powerlessness are addressed within the disability literature. However, following the argument presented in Chapter 1, exclusion and oppression are not fixed issues for disabled people. People with impairments are not necessarily affected by oppression and exclusion, as their impairments will not necessarily interact with the physical and social world in a way that creates disability. Additionally, there is also a body of literature which explores how disability identities do not always need to be thought about in negative terms of oppression and exclusion. The two main two strands of this literature focus on affirmative self identities, as typified by Swain and French's (2000) approach, there is also a growing body of literature which focuses on emancipatory practices that enable disabled people to empower themselves and challenge oppressive and exclusionary practices (Goodley 1997; Evans 2004; Shakespeare 2006b). These issues will be revisited later in the thesis as affirmative self identities are important to the analysis of the data collected in this study, and issues of empowerment are important to the research paradigm and methodologies employed.

### ***The Affirmation Model of Disability***

The affirmation model is described by Swain and French (2000, 569) as a 'new model of disability [...] emerging within the literature'. They describe it as 'a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled' (Swain and French 2000, 569). They claim that it has arisen 'in direct opposition to the dominant personal tragedy model of disability and impairment, and builds on the

liberatory imperative of the social model' (2000, 569). They assert that disability is not necessarily about negative issues as it can be something to be embraced and celebrated, stating that 'non-disabled people can generally accept that a wheelchair user cannot enter a building because of steps. Non-disabled people are much more threatened and challenged by the notion that a wheelchair user could be pleased and proud to be the person he or she is' (2000, 570).

Therefore, their model aims to challenge society's views of disability, and they argue that disabled people are proud of their bodies and achievements in life. Corker (1998) similarly states that affirmation about disabled people's identities is most readily found in the disabled people's movement, disability arts and in Deaf culture.

It could be argued that this is not really a new model of disability, as its perspective on the complexity of nature of impairment and disability is rather reductionist, highlighting only the positive issues relating to disabled people's impairments and lives. It does, however, raise an interesting alternative perspective to the tragedy-focused way of thinking about disability, which will be important in the analysis of some of the data that came out of the study.

## **Disability Empowerment**

An important issue that runs through the disability literature is how disabled people can be empowered through research (Barnes 1992a; 2001; Oliver 1992; Stone and Priestley 1996; Priestley 1997; Kitchin 2000). This body of literature will be discussed in Chapter 4, as it underpins the research paradigm and methodologies employed in this study. However, research is just one

conduit to facilitating disabled people's empowerment, and at this point it is useful to reflect back on the definitions of the term empowerment as presented in Chapter 1. Solomon (1976, 6) defines the term by describing it as an active process, stating that 'empowerment refers to a process whereby persons who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skills in the exercise of interpersonal influence and the performance of valued social roles'. This highlights the relational nature of power as discussed by Thompson (2001). Adams (2003) describes levels at which empowerment can occur: individual, interpersonal, group, organisational and community, which provides a useful framework when considering the types of empowerment that disabled people may engage in.

There are parallels to these perspectives in the disability literature. Oliver (2009, 102) describes empowerment as a 'collective process of transformation on which the powerless embark as part of the struggle to resist the oppression of others, as part of their demands to be included, and/or to articulate their own views of the world'. This can be seen to describe the political struggle that the disability movement has been involved in over the last 40 years, with Hahn (2002) describing empowerment as an opportunity for disabled people to achieve equality in society. Issues such as the disability movement lobbying for legislation to give disabled people fundamental rights within society is an example of Adam's (2003) notion of empowerment of the disabled people at the community level.

Organisational empowerment for disabled people can be described by some of the changes within the disability charity sector. Shakespeare (2006b) discusses how in the past, disability charities were run on *behalf* of disabled people, and

did not involve them in shaping the organisations' agendas. He explains how some charities now involve disabled people more centrally. For example, the Royal Association of Disability and Rehabilitation now has a majority of disabled people on its management committee, along with a disabled person as Chief Executive. This means that disabled people are in control of the charity's priorities and vision at the organisational level.

Evans (2004) discusses empowerment in terms of how user-led consultation with disabled people has transformed independent living services and supported improvements to disabled people's lives. For example, he describes the process of groups of disabled residents within sheltered accommodation 'seizing back' power from local authorities so that they can make decisions about the support that they need to live independently. This example is a good illustration of Adam's (2003) group level of empowerment.

The lines between interpersonal and personal empowerment are rather blurred, as it could be argued that personal empowerment involves interaction with other people. In relation to this issue, Goodley (1997) describes how the development of self-advocacy skills for people with learning impairments has enabled them to gain an empowering voice, allowing them to challenge the problems they face in their lives. However, Goodley (1997) only briefly overviews the support given to people with learning impairments that can enable their self-empowerment, and it is a feature of the literature that methodologies involved in how to undertake disability empowerment are not discussed in detail. The levels at which disability empowerment can occur within society show the variety of ways that disabled people can be supported to empower themselves.

## **In Summary**

Goodley (1997, 372) states that 'understandings or discourses of disability are fluid, ever-changing and dynamic' and, as Barnes (2000, 441) asserts: 'There is little doubt that during the latter half of the 20th century our understanding of disability and the complex process of disablement has been transformed'. This sentiment can also apply to the early part of the 21st century. The growth of the UK disability movement and its call for society to acknowledge disablism alongside other forms of oppression have been significant, along with the rise of disabled people taking ownership of how disability is defined and conceptualised. The separation of impairment and disability as separate but interconnected issues within the DPI's (1982) definition of disability was a significant step forward, as was the development of the social model.

In Shakespeare and Watson's (1997) view, the social model has had a limited impact on society, and more work is needed to implement it. They feel that renewed attempts to win acceptance of the model within wider society should be the main emphasis of activity, rather than 'nit picking and navel-gazing' (1997, 263). In a time of austerity, the focus on challenging disabled people's exclusion, challenging unequal and oppressive power relationships and empowering disabled people to fight for their rights has never been more important. In the next chapter, the discussion will move on to look at the museum context of the research question, and matters relating to disabled people's access, inclusion and engagement in museums will be examined in more detail.

## **Chapter 3: Social Inclusion, Anti-Oppressive Practice**

### **Museums**

#### **Introduction**

This chapter draws on the broad issues of social exclusion and oppression discussed in the two preceding chapters, and explores how museums have aimed to address them through socially inclusive and anti-oppressive practices. As this thesis has a central focus on the relationship between these issues and disability, it will move on to explore museum practice in this area. This chapter demonstrates how museums do not always prioritise issues of social inequality within their core goals, as work in this area can be peripheral in nature (Black 2006; Lynch 2011b). It will show that there are pioneering museums that display genuine commitment to the mainstreaming of equality issues, and which are willing to take risks and invite external groups into their organisation in order to challenge exclusionary museum practices (Lynch 2007; 2011a; 2011b; Watson 2007). However, the chapter also discusses the gap in the literature around how museums can work with individuals and communities to support their self-empowerment.

First, to inform the debates around inclusive museum practice for disabled people, a wider body of museum literature will be drawn upon that explores how exclusionary practices were built into museums from their conception, and how this was linked to wider issues within society (Bennett 1995; Witcomb 2003; Weil 2007). It will then move on to look at the paradigm shift that occurred in museums beginning in the 1980s, which re-orientated their priorities around the

needs of communities, described by Vergo (1989) as ‘the new museology’. This will lead onto an exploration of the range of barriers that prevent people from engaging with museums, as well as recent advancements in practice that have witnessed museums working in more participatory ways that aim to share power with marginalised communities (Govier 2009; Lynch and Alberti 2010; Simon 2010; Lynch 2011a; 2011b). These broader issues will serve as a useful context for an examination of museum practice in relation to disability, which will be the focus of the final section of the chapter. Overall, this chapter will aim to position the study within the wider museums context.

## **Origins of the Public Museum and Power Relations**

In the UK, the origins of the public museum can be traced back to the opening of the Ashmolean Museum in Oxford in 1683 (Abt 2006), although the formation of the museum as an institution that we would recognise only began in the early part of the nineteenth century. In his book *The Birth of the Museum*, Bennett (1995) talks about this period of expansion and argues that objects, and the knowledge contained within them, were placed on public display for the first time. He discusses the public nature of museums, and how one of the founding principles was to see people from different social strata mixing within the museum space.

For the Victorians, the pinnacle of Western knowledge lay in the study of works of art, antiquities, geological and biological specimens, rare books and ancient manuscripts. ‘Those who possessed the wealth to acquire great collections also possessed the civic influence and social connections with other like-minded leaders to found cultural institutions’ (Abt 2006, 130). As Abt points out, the

wealthier classes spent fortunes acquiring vast collections in order to gain this influence. Museums became repositories of objects, and acted as the custodians of the knowledge enshrined within these objects. Museums became places where the middle and upper classes could visibly amass social capital through their philanthropy and their social connections. This benefit of social capital for the 'elite' classes is discussed by Bourdieu and Wacquant (1992) and Bourdieu (1997).

The ruling classes also envisaged a role for museums as part of civic reform, seeing them as places where their worldview could be communicated to the masses (Bennett 1995). Thus, the intermingling of people from different social strata had a specific agenda behind it. In the context of rapidly growing industrial cities, museums were pedagogical institutions that had a role 'alongside the penitentiary, the police force and slum clearance in reforming newly formed populations into a modern citizenry' (Witcomb 2003, 80). Bennett (1995) and Macdonald (1998) build on the work of Foucault (1977; 1979) to explore the relationship between knowledge and power in the 'civilising role' of museums. Bennett (1995, 94) talks about how museums were used as 'a vehicle for the display of power' by the ruling class in order to promote the dominant culture's world view and authority. As Weil (2007, 32) asserts:

The museum was established to 'raise' the level of public understanding, to 'elevate' the spirits of its visitors, and to refine and 'uplift' the common taste. There was no ambiguity in this. Museums were created and maintained by the high for the low, by the couth for the uncouth, by the washed for the unwashed, by those who knew for those who didn't but needed to know and who would come to learn.

Hence, the museum's role was part of the mechanism that upheld the values of the dominant ruling class, described by Gramsci as the 'dominant hegemony'

(Ives 2004). The objects that museums chose to collect, and the way that they chose to display them, placed the institution of the museum in a position of power and authority. Bennett asserts that museums were intended 'for the people', but were not 'of them' (1995, 109). He explains how during the Victorian period the social history of working class people was excluded from museum narratives. Bennett (1998) goes on to argue that although philanthropic liberal individuals who were concerned with 'good works' often created museums, the museums themselves were essentially designed to highlight differences between groups, and thereby reinforced inequitable power relations. These issues were built into the very fabric of the institution, from the architecture to the expectations of how visitors should behave within their walls. The legacy of these issues of power and inequality lay at the heart of modern museums, and today, museums are not unaware of the power they hold to include and exclude individuals and groups within society. A radical shift was needed to move museums from an elitist and exclusionary position to a place where they could demonstrate more egalitarian principles. This reorientation of purpose began in the 1980s with what Vergo (1989) calls the 'the new museology'.

### **'The New Museology'**

Vergo states that in contrast to 'the new museology', 'the old museology' was 'too much about museum methods, and too little about the purposes of the museums' (1989, 3). Macdonald (2006) elaborates on this issue by asserting that the 'old museology' was more concerned with practical matters of administration, education or conservation rather than the need to explore the conceptual foundations and assumptions behind the museums' aim of engaging

with people. This paradigm shift instigated a process of professional reflection on which communities were represented within the museum space, and which communities were excluded. As Fleming (2001) argues, museums became increasingly interested in representing the lives of ordinary people, and in so doing became more community-oriented. Witcomb suggests that:

By placing 'community' at the heart of the museum enterprise, the argument runs, it will be possible to overcome the role of museums as hegemonic institutions. In giving voice to the powerless, a process of self-discovery and empowerment will take place in which the curator becomes a facilitator rather than a figure of authority (2007, 133).

Here, Witcomb explores a complex range of issues relating to authority and disempowerment, and voice and empowerment, which will be unpacked in more detail later in this chapter. At this stage, it is useful to recognise that Witcomb's aspirations point to the relationship that can potentially develop between museums and the community. As discussed by Stam (2005, 54-55), the new museology called for 'change, relevance, reorientation and redistribution of power'; it now 'regards museums primarily as social institutions with political roles'. The view that museums have a political role within society was an important development, as it set in motion a fundamental process of reflection on the role that museums can and should play in society.

This process of professional reflection was set against a backdrop of the emergence of the civil rights movements in the UK. Lavine (1992) argues that in response to the civil rights movements of the 1960s and 1970s, every institution that was seen to hold power was questioned, including cultural organisations, and the idea that museums were benignly neutral institutions was lost. In particular, the concept of difference in terms of inequalities in ethnicity, gender,

sexuality, and class became important (Macdonald 2006). Identifying disabled people alongside the communities discussed by Macdonald, Barrett (2011, 4) states that new museology became 'a key way of thinking about the way in which audiences are differentiated and organized into categories of disadvantage'.

When thinking about how to facilitate change for groups in society who are affected by disadvantage, a key discourse in the museum literature focuses on the potential for museums to act as 'agents of social change' (Sandell 1998; 2002a; 2003; 2007; Newman 2001; Newman and McLean 2004a; 2004b; Silverman 2002; Janes and Conarty 2005). The idea of 'a change agent' is discussed extensively in the literature relating to organisational change within the field of management studies, in the form of an individual who facilitates or drives change within an organisation (Elliot-Kemp 1982; Conner 1992; Green 2007). Within museology this concept is applied to the way that museums can act to bring about changes within society. Hence, it acknowledges the cultural, social and political roles of the museum. It raises questions about how they can act to address exclusionary practices, and what place they might have alongside other organisations that seek to combat social inequalities.

The notion that museums have a responsibility to combat social exclusion is well documented (Newman 2001; 2006b; Fleming 2002; Silverman 2002; 2010; Sandell 2002b; 2007; Newman and McLean 2004b). However, the argument that this should be a central component of a museum's purpose and the suggestion that this is an appropriate use of museum resources have been called into question (Cuno 1997; Appleton 2001; Rassool 2006). On the one hand, critics such as Appleton (2001, 7) argue that 'museums should stick to

what they do best – to preserve, display, study and where possible collect the treasures of civilisation and of nature'. Appleton (2001) is explicit in arguing that it is not the place of museums to be concerned with social or political issues in society. She states that within people-centred museums:

social ends tend to take over. Much of the activity of museum staff is now indistinguishable from that of a host of social, health or educational services. Most of the DCMS or GLLAM case studies of best social inclusion practice could have been performed by any charity or social service. The collection and the specialist knowledge required to understand it are pushed to the margins (Appleton 2007, 122).<sup>7</sup>

However, it can also be argued that this position disregards the potential of collections to connect with people, and raises the question of how they can be used within marginalised communities to give them a voice within society.

Sandell (2007, 10) contends that 'museums have an obligation to deploy their agency in ways which respond to (and seek to influence) societal values'. Given that the social model of disability is the theoretical underpinning of this thesis, it is clear that this study is in alignment with the perspective that museums have a responsibility to tackle the barriers which prevent disabled people from engaging with them, and therefore have a responsibility to act as agents of social change.

## **Barriers to Access and Inclusion**

Many authors discuss the factors that might exclude individuals and communities from buildings, exhibitions and programmes (GLLAM 2000; Black 2006; Silverman 2010; Nightingale and Mahal 2012). As will be discussed, a range of publications highlight a series of barriers that can prevent some individuals and communities from accessing museums. The concept of barriers

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<sup>7</sup> The acronyms are: Department for Culture, Media and Sport (DCMS) and Groups for Large Local Authority Museums (GLLAM).

to disabled people's engagement in society was established in Chapter 2 (French and Swain 2012). In the context of museums, the Scottish Museums Council (SMC), for example, asserts that 'strategies to enable museums to become more inclusive and to contribute to the wider goal of tackling social exclusion need to address in detail why people do not use museum services' (2000, 6). Therefore, it is important for museums to identify what barriers prevent different communities from accessing their services, and for them to proactively work on dismantling them. Analysis of the museum literature that focuses on barriers to access (Dodd and Sandell 1998; DCMS 1999; 2000; SMC 2000; Research Centre for Museums and Galleries [RCMG] 2004) identifies the following categories:

**Institutional barriers** can be created consciously or unconsciously by museum staff. They can create exclusionary practices that discourage or restrict people from accessing museums. For example, a lack of diversity training may lead to discriminatory practices. Acquisition and exhibition policies may not reflect marginalised communities' material culture, and therefore may lead to their underrepresentation within museum collections and spaces.

**Personal, social or awareness barriers** can prevent individuals from accessing information about the museum. This issue was particularly highlighted in the 'Not for the Likes of Us' report (RCMG 2004), which discusses the question why people may feel that museums are 'not for them'. This category can overlap with institutional barriers, as it can also include staff attitudes. For example, young people might feel uncomfortable in a museum if they are being watched and followed by staff who are suspicious of them. Personal barriers can

also occur when people are unable to read textual displays or communicate with museum staff.

**Physical or geographical (environmental) barriers** can occur due to the geographical area in which the museum is situated. For example, some museums may be located in rural locations with poor transport links, and therefore people who do not own a car cannot easily travel to them. Physical barriers might include long flights of steps at the front entrance, which make it difficult for people with physical impairments to enter.

**Sensory barriers** occur if museums do not consider the needs of people with visual or hearing impairments. For example, museums may overlook the need to include captioning and/or British Sign Language interpretation on audio-visual presentations to facilitate access for Deaf people.

**Intellectual barriers** occur if museums do not consider the background knowledge or cognitive needs of visitors. For example, museums might use inappropriately elitist, academic, technical or jargonistic language in exhibitions. This will exclude anyone who does not have the specialist knowledge needed to interpret the displays, and could even lead to feelings of inferiority.

**Financial barriers** can be created by museum admission policies. The level of entrance fees to the museum or special events and the pricing policies in their shops and cafés might exclude people on lower incomes or benefits.

**Cultural and representational barriers**, as identified by RCMG (2004), are a complex issue for museums to consider, as doing so will involve the museum identifying whether different communities are represented within their collections, exhibitions, programmes and staffing profiles. For example, in cities

with large ethnic minority populations, the museum staff might not reflect the diverse demographics of the local area and the museum might not represent marginalised communities in its collections, displays or programming. Lang (2006, 33) quotes Hall<sup>8</sup> (Arts Council England 2000), who explains the importance of this issue when he says that ‘museums are a mirror for society; if you don’t see yourself reflected in that mirror you cannot feel that you belong’.

**Technological barriers** can prevent some people from accessing the museum’s website, the social media networks on which the museum has a presence, or the technology involved in exhibition interpretation. For example, the Museums, Libraries and Archives Council (known as MLA) web accessibility audit found that only 1% of museum websites met the legally required standards of access (Petrie, King, and Hamilton 2005).<sup>9</sup>

**Barriers to decision making**, as highlighted by Dodd and Sandell (1998) and RCMG (2004), could be said to underpin the other issues. If marginalised communities are not involved in the decision-making processes within the museum as users and stakeholders, their needs and interests will not be identified, which would prevent exclusionary practices from being challenged.

Therefore, it can be said that the museum sector has a good understanding of barriers to access, and Black (2006) explains the importance of working in collaboration with communities to dismantle them together. It is this sense of

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<sup>8</sup> From Hall’s keynote speech to the ‘Whose Heritage?’ conference in 1999.

<sup>9</sup> The ‘Web Handbook. Checklist: Universal Accessibility’ (e-Government Unit 2005) outlines the legal requirements that all public-sector websites must meet under the Web Content Accessibility Guidelines at Level AA. These guidelines were produced for the World Wide Web Consortium’s Web Accessibility Initiative. They include a raft of technical specifications that must be included in the way that websites are built and designed to ensure that they are accessible to disabled people. Level AA is the medium level of accessibility within this set of standards.

museums working in a collaborative relationship to tackle barriers to access that this fieldwork explores.

### ***Balancing the Needs of Multiple Communities***

Nightingale and Mahal (2012) raise an additional dimension for consideration in relation to access barriers. They discuss the challenge of balancing the needs and interests of multiple communities, and how sometimes museums prioritise the needs of one group over another. This could have a negative impact on the communities that feel that their needs are not prioritised. This is a very real consideration for museums when balancing the needs of multiple communities with differing needs and interests, some of which may be part of the museums' core audience and some of which may be marginalised by barriers to access. Thus, when considering the needs of different communities, museums should look at this issue from a holistic viewpoint. This approach creates an added layer of complexity to the goal of creating inclusive spaces and services. Nightingale and Mahal (2012, 13) assert that:

many institutions interpreting their responsibilities in this area as being limited to one area of activity (for example, collections or staffing) or restricted to specific equality issues (such as race, gender or disability) with a corresponding disregard for the interconnections or tensions between them.

The methods taken to address inequalities can consequently take a considerable amount of thought and commitment. *The Journey* exhibition, which formed part of the work that the Pioneers group engaged in at The Holocaust Centre, was the first exhibition in Europe that aimed to explore the Holocaust with primary-aged schoolchildren (THC 2005b). The stakeholders who were consulted during the exhibition planning process included:

- Primary school teachers and pupils: who were the principle audience for the exhibition.
- Holocaust survivors: as it was important that their stories were represented in a sensitive way.
- Young disabled people: as the exhibition narrative explored issues of prejudice, stigma and exclusion it was important that disabled schoolchildren were able to experience and access the content alongside their non-disabled peers.

In accordance with Nightingale and Mahal (2012), the need to balance these key stakeholders' needs and interests within this exhibition space was a challenge for the Centre, and this issue will be explored further in analysis of the data in Chapter 6.

When considering whether museums are able to work in this complex way with communities, it is interesting to explore where their work with marginalised communities is situated within their organisational priorities. Is this work sited at the core of the museum, or at the margins? And does the positionality of this work have an impact on the museum's ability to address inequalities?

### **Challenging Inequalities: At the Margins or the Core?**

Museums show a diverse range of approaches to engaging with marginalised or excluded communities. Engagement can be achieved through exhibitions, education programmes, events, contemporary collecting and community development or outreach work (Black 2006; Lang, Reeves, and Wollard 2006; Davis 2007). However, a mixed picture emerges from the literature in relation to

the way that museums undertake this work and its effectiveness in combating inequalities. As outlined by Nightingale and Mahal (2012, 13): 'some organisations have genuinely tried to embed diversity and equality across their organisation; to engage staff at all levels; to draw on the expertise of stakeholders outside the institution in order to respond to changes within society'. Conversely, other authors such as Black (2006) discuss the shortcomings in museum practice in this area. Black highlights the issue that a large proportion of work in this area is project-based. Although he acknowledges that this has led to many individual successes, he also has serious reservations about this approach as 'projects by their very nature are both short term and peripheral to the core activities of the museum' (Black 2006, 62). When discussing the implications of this approach, Lynch (2011b) states that short-term funding prevents museums from creating long-term strategic approaches, and makes it difficult for museums to build sustainable relationships with marginalised communities.

The emphasis of peripheral outreach work can be on taking 'the museum' out to the community. Whilst this is an appropriate first step, there is limited evidence that outreach work is able to challenge inequities in the core working practices (Hollins 2010a). Lavine (1992, 137) states that 'these efforts result most often in occasional exhibitions and special festival programs centred around themes designed to appeal to certain groups. Museums hope these efforts, along with their outreach programs, will win new audiences for their regular work', which highlights museums' motivation behind this approach. However, as cited in Black (2006), Matarasso (2000, 5) has strong reservations about this issue, stating that 'it seems illogical to believe that a response to social marginalization

which is itself marginal to the service promoting it can have a serious or sustainable impact on the problems it has identified’.

Nightingale and Mahal (2012) discuss the importance of having a member of staff whose specific remit is to focus on embedding diversity and equality across the organisation. In their research they found that most of the museum’s relationships with the 80 black, Asian and minority ethnic organisations who had worked on projects with the Victoria and Albert Museum (V&A)<sup>10</sup> did not extend beyond the temporary project staff members, many of whom subsequently left. Nightingale and Mahal expand on this issue, stating that: ‘organisations who have worked collaboratively with museums and galleries may often feel “dropped” when the special exhibition or programme is over’ (Nightingale and Mahal 2012, 24). This may undermine the communities’ long-term trust in the museum. Black (2006, 62) asserts that: ‘ambitions to develop museums as inclusive institutions will remain no more than aspirational until they are absorbed into both the ethos and the senior management teams’, and that ‘the long-term and resource heavy nature of this commitment must be fully appreciated and supported’. In Chapter 6, one of the issues that will be highlighted by the data is the need for strong leadership to support changes to working practices. This thesis will also explore the resource implications of undertaking in-depth long-term work with communities.

What is lacking from this type of approach is an acknowledgement of the issues around power, control and authority that were explored in Chapter 1. When working on outreach projects or special events the core practices of the museum are not generally challenged, although some of the barriers to access might be

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<sup>10</sup> Nightingale and Mahal work at the V&A.

understood in more detail. The power, control and authority lie with the museum, and communities are only involved as passive participants in activities.

Communities have activities 'happen to them', rather than with them. At this stage, it is worth revisiting Phillipson's (1992) definitions of anti-discriminatory and anti-oppressive practices, as described in Chapter 1. Phillipson indicates that anti-discriminatory practices focus on the removal of barriers to access from within the existing power structures of an organisation. In comparison, anti-oppressive practices are more radical, as they aim to challenge the existing power structures and the inequalities in relationships that can create oppression. For example, an event that includes British Sign Language interpreters to enable Deaf and hearing impaired people to understand its content would be viewed as an anti-discriminatory practice, as it would tackle a barrier to communication. However, the opportunity for Deaf and disabled people to enter into a dialogue with senior management to shape the future direction of provision would be classed as an anti-oppressive practice. Whilst it is helpful to communities to offer solutions to specific barriers, this approach can lead to a piecemeal and limited response to the underlying issues behind their exclusion and/or oppression. For example, providing an interpreter for Deaf people at an event does not mean that the entire visit to the museum is accessible.

Further examples of anti-oppressive practices which aim to involve marginalised communities in museum developments will be discussed later in this chapter. However, at this stage it is useful to explore how museums might engage in more in-depth ways with communities; ways that go beyond outreach.

## Types of Community Participation in Museums

Simon, in her publication *The Participatory Museum*, argues that when people actively participate with cultural institutions ‘those places become central to cultural and community life’ (2010, ii). She believes that inviting people to actively engage as cultural participants, rather than as passive consumers, enables museums to reconnect with the public and demonstrate their value to contemporary society. She defines a participatory cultural institution as ‘a place where visitors can create, share, and connect with each other around content’ (2010, ii). Simon views the museum as a meeting ground for dialogue about content, and thinks museums should collaborate with users over content creation. The focus of Simon’s work is on how museums can engage with communities through the use of social Web 2.0 technologies<sup>11</sup> to create a two-way dialogue. Her ideas on participation can be applied across the museum, particularly with the development of exhibition content. Janes (2007) discusses ‘wisdom’ in the context of the knowledge that is held about objects and collections by marginalised communities. He calls for community knowledge to be valued stating that ‘the so-called experts must also be continually questioned’ (2007, 143). Local and diasporatic communities may know a lot about the context of the objects that the museum may be unaware of, and therefore should be able to add new knowledge to the collections. As Janes (2007, 143) states: ‘There is inherent and enduring value in local, traditional and experiential knowledge, and it is increasingly important that these resources be respected and used’.

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<sup>11</sup> The term social 2.0 Web technologies refers to websites and other Internet-based platforms such as wikis, blogs, social networking or video-sharing sites where users interact and collaborate with each other to create user-generated content in a virtual community.

The issue of the authority and expertise of the museum being questioned mirrors a theme which runs through the disability literature about the need to value disabled people's embodied knowledge about their impairments, and how this can often be overlooked in favour of expert opinions (Morris 1991a; Kitchin 2000). Disability academic Barnes (1992a, 123) talks about the need to 'erode the myth of the "professional expert"', which is a view in alignment with both Janes (2007) and Simon (2010). This perspective also parallels the work of Freire (1972), as discussed in Chapter 1, who states that oppressed peoples are the ones who are in the best position to understand the consequences of oppressive practices.

Simon believes that 'participatory institutions are created and managed "with" visitors' (2010, iii). She discusses four types of participation that individuals and communities may engage in with museums. Cited in Simon (2010), three of these types of participation are taken from the 'Public Participation in Scientific Research Project' report produced by the Center for Advancement of Informal Science Education (Center for Advancement of Informal Science Education 2009). This report defines the three broad types of public participation in scientific research as 'contribution', 'collaboration' and 'co-creation'. The fourth type is put forward by Simon as engagements that can be described as 'hosted'. Simon applies these ideas from the realm of science research to the cultural context, and in so doing creates the following definitions of these terms.

- 'Contributory' projects invite visitors to contribute to the museum by providing objects, ideas or actions but the institution stays in control of the process and outcomes.

- ‘Collaborative’ projects invite visitors to become active partners, but the museum also remains in control of the process and outcomes.
- ‘Co-creative’ projects involve community members working with museum staff from the beginning so as to define the project’s goals and create its outcomes, for example, on community-focused exhibitions.
- ‘Hosted’ projects see the museum turning over a portion of its facilities and/or resources to present programmes developed and implemented by communities.

Simon elaborates on this issue by stating that ‘no one model is better than the others. Nor should they even be seen as progressive steps towards a model of “maximal participation”. There is no “best” type of participation in cultural institutions’ (2010, 188). Simon also states that this way of working should be just one of many tools in the museum’s ‘tool box’, and that museums might not choose to work in a participatory way on every project.

These ideas present a useful framework for thinking about the depth of participation that communities could engage in when working with museums. However, what this approach does not explore is the extent to which a given community benefits from its involvement, or whether individuals and the wider community are empowered by their engagement. Simon (2010) does not focus on issues of oppression, exclusion and marginalisation in her work, which may explain why this is not central to her ideas. She is interested in how museums can engage with all visitors to create a more equitable space for dialogue.

This non-engagement with issues of power also threads through Govier’s (2009, 4) definition of co-creation: she states that ‘co-creation fundamentally means

museum and gallery professionals working with our audiences (both existing and potential) to create something new together'. She argues that 'co-creation does not necessarily have to be largely about a community's agendas, and power shared with that community as equally as possible' (2009, 3). This issue of co-creation and its association with power-sharing will be explored further in the next section, as it is important when considering the nature of engagement within the case study.

The term co-creation is often used interchangeably in the museum literature with the term co-production. As with Simon's (2010) definition of co-creation this type of work involves museum staff and community members working together from the outset to create goals and outcomes for museum work, with both partners seeing the work through to completion. As discussed by Davies (2010) co-production most commonly occurs within the development of temporary exhibition programmes, where museum staff and communities work together to develop the design and content of an exhibition space. For example, they may work collaboratively to choose objects from the museum collection and jointly craft and implement the exhibition design brief. However, co-production could extend to any area of museum work from the development of new marketing materials through to the development of learning programmes. Govier (2009) defines co-production as an activity where the museum and community create new museum content together.

The next section will highlight issues of power-sharing as authors such as Lynch and Alberti (2010) and Lynch (2011a) focus on whether co-production is based on an equitable relationship where the museum aims to share power with the community over the exhibition's agenda. However, Govier (2009) does not

connect issues of power-sharing with co-production. These issues of power-sharing and co-production are important as they will be revisited as part of the analysis of the data in Chapter 5.

### ***Community Consultation, Power-sharing and Museums in the 'Contact Zone'***

Govier, who is a proponent of co-productive work with communities, states that the association of co-production with the need to share control and power with communities is 'something of a red herring' (2009, 4). She criticises the ideas put forward by Lynch (2007) around co-productive projects and power, as she believes this reduces the debate to a question of 'democracy versus elitism, when it is more complex and nuanced than that' (Govier 2009, 4). She asserts that 'in reality, museums are very unlikely ever to give up all of their control' (2009, 4). However, in relation to marginalised communities it can be argued that the issue of power-sharing is important. If the agenda, power and control remain with the museum, then exclusionary practices in relation to co-production will not be challenged.

Simon (2010) insists that it is unrealistic for museums to enter into in-depth, challenging and consultative relationships over every area of museum activity. For example, a piece of consultation about the refurbishment of a museum's teaching space might only need some basic consultation with teachers to elicit their input. Cornwall (2008a) discusses how some groups are able to confidently negotiate relationships with public institutions, as issues of inequality do not come into play when such groups already have the skills and agency to navigate

the terrain. Cornwall also discusses how marginalised communities may not want to enter into in-depth relationships that involve the sharing of power.

However, in relation to co-productive and collaborative relationships with marginalised communities, my position is that issues of power should be discussed and negotiated. I think it is rare that issues of power and control do not come into play with marginalised communities, due to issues of exclusion and oppression (as discussed in Chapter 1). Whilst Govier (2009) is critical of Lynch's (2007) ideas about power-sharing, I think the reflective and candid work of Lynch and Alberti (2010) and Lynch (2011a) encapsulate the reasons why co-production should be linked with power-sharing when museums work with marginalised communities.

Lynch and Alberti (2010) and Lynch (2011a) discuss the tensions, frustrations and conflicts that arose during the co-production of an exhibition with the local black community in Manchester<sup>12</sup> in the run up to the Bicentenary of the Abolition of the Slave Trade, and how these tensions arose due to issues of power and control. Their frank unveiling of the tensions is comparable to Lagerkvist's (2006) discussions of a similar experience at the Museum of World Culture, Goteborg (Sweden) where the local black community came into conflict with the museum over the development of an exhibition. In both cases, the museum staff were unprepared for the process that unfolded or how the legacies of oppression, and contemporary issues of race would have an impact on the unfolding relationships. Both organisations ended up questioning whether unintentional institutional racism had played a part in the uncomfortable nature of the relationship.

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<sup>12</sup> Lynch was Deputy Director of the Manchester Museum during the time of the exhibition's development.

Lynch and Alberti (2010) and Lynch (2011a; 2011b) went on to unpack a series of issues relating to the extent to which museums are willing to share power with communities. Lynch (2011a) contends that, although museums may aim to share power, they often fall short, as staff are unwilling to let go of their control and authority. She also explains that this often happens even when it is their intention to do so. Govier (2009, 4) agrees, suggesting that 'in reality, museums are very unlikely ever to give up all of their control'. Whilst this may be true of many institutions, Lagerkvist (2006), Lynch and Alberti (2010) and Lynch (2011a) present examples of museums that are willing to take this risk with the aim of trying to develop more equitable relationships with marginalised communities.

Lynch (2011a) draws on Clifford's (1997) ideas about the museum being a 'contact zone' in order to describe the type of community consultation where issues of inequality come into play. Clifford (1997) borrowed the term 'contact zone' from Pratt, who developed it in the context of colonial history to get away from the binary 'centre/periphery model' of working with communities, where the museum is at the Centre of power and the community is on the periphery (Witcomb 2007; Lynch 2011a). Parallels can be drawn between this aim to share power in the 'contact zone' and Arnstein's (1969) Ladder of Participation, as discussed in Chapter 1. Arnstein describes how communities can be involved in the planning and implementation of organisational change. In this model, at the lowest level people are coerced into 'rubber stamping' the institution's ideas, whereas at the highest level power is shared or even handed over to communities. This way of working challenges the issues of control, authority and power that are problematic in a peripheral museum outreach approach.

Clifford sees the 'contact zone' as a place of negotiation and conflictual discourse and of a 'push and pull' scenario (1997, 192). It is a space where cross-cultural experiences and differences come into contact. My interpretation of this 'contact zone' is as a space where two groups could come together that may have different priorities, different perspectives on the situation, and different cultural practices. At some point in the ensuing discussions it is inevitable that disagreements will take place, and it is only by finding a common language, ground and goals that these groups will move forward. This will involve building trust and respect, along with creating an equitable relationship where issues can be worked through to secure a resolution; or at least where differences of opinion can be respected. If the community involved is not experienced in voicing their opinions and challenging institutional practices, then they should be supported in a way that enables them to develop the skills and confidence to lobby for change. On this subject, Cornwall (2008a) asserts that organisations need to do more than simply invite communities to the table, as this 'is by no means sufficient to ensure effective participation. Much depends on how people take up and make use of what is on offer, as well as on supportive processes that can help build capacity, nurture voice and enable people to empower themselves' (2008a, 275). The issue of the relationship between community empowerment and power-sharing will be explored in the next section. This type of relationship takes time to develop and, as described by Lynch and Alberti (2010) and Lynch (2011a) it can develop through what they call the sharing of 'radical trust'.

This 'radical trust' is built when museums enter into a democratic and participatory relationship with communities; when the museum understands that

it cannot have control over the outcome of developments. Relinquishing control involves an element of risk, which can be a large step for museums to take when they are not used to sharing an agenda with an external organisation. As stated by Nightingale and Mahal (2012), museums also need to be open to external influences, which relates to the concept of social capital (as presented in Chapter 1). As previously discussed, communities with greater social capital will be in a better position to sway decision-making than those who lack this resource. Therefore, the relationship between the museum and the community needs to be on a more equitable footing if external influences are to be valued.

When thinking about how museums engage in consultative exercises with communities, Witcomb (2007) draws on Clifford (1997) to state that museum practice generally belongs within the centre/periphery model, as the museum collects advice from the community but is free to choose whether it acts on the information received. This is confirmed by Watson (2007, 14-15) who describes the current picture of the practice from the sector:

While museums increasingly consult with such groups, power [...] still rests firmly with the museum. While many local history museums in the United Kingdom show sensitivity towards their local communities and engage in various types of consultation when developing their displays, others do not. At best they obtain some oral history stories on topics predetermined by a display team meeting.

Watson (2007) goes on to explain that there are some exceptional organisations who aim to share decision-making with communities. However, overall the picture of museum practice is described by Lynch (2011a; 2011b) as 'empowerment-lite', a term she borrows from Cornwall (2008b), who coined it to describe how organisations use their power to control the extent to which they invite communities into a relationship. Cornwall (2008a, 280) also states that

organisations need to be clear about what involvement in decision-making actually means, as it can imply that 'all and any decisions are up for grabs'. Negotiating the sharing of power and deciding who has the authority, experience and knowledge to make different decisions can be a complex business. Lynch (2011b) describes how museums need to be more reflexive in their approach if they are to create more equitable relationships. She asserts that there is a need for staff to build 'dialogical skills and techniques, if they are to build trust and learn from their own practice' (2011a, 158). As will be seen later in the thesis, this is an issue which arose during the fieldwork.

## **Community Empowerment**

When considering the issue of community empowerment in the museum context it is useful to revisit Wallerstein (1992), who in Chapter 1 described empowerment as an active process of engaging people as a way to support them in gaining control and power, thereby enabling them to improve both their quality of life and their political position within society. This understanding of empowerment could be applied to power-sharing and co-productive work as described by Lynch and Alberti (2010), Simon (2010) and Lynch (2011a). As described in Chapter 1, the literature does not offer easy solutions or step-by-step strategies to follow in relation to supporting the self-empowerment of individuals or communities. Wallerstein (1992) states that there is no perfect model of how to undertake empowering practices. This might be due to the complex nature of the processes involved, and also the complex needs of different communities. However, although there is no overarching framework, the literature does describe a series of issues with reference to empowerment

practices, and it is encouraging to see that the museum sector has some insightful ideas to add to the debate.

Silverman (2010) focuses on empowerment in her assessment of the *Social Work of Museums*, and draws parallels between the work of social workers and that of museum staff, both of whom enter into relationships with individuals and groups with the intention of creating positive change in their lives. Silverman examines ideas about empowerment at the individual, group and society levels. However, her discussion is a mixture of broad ideas, concepts and activities, all of which museums can be involved in, and therefore her work is far from offering a 'blueprint' of how museums can enter into empowering practices. Admittedly, she does not claim to be giving this level of guidance, and the ideas that she presents generate the most complete museum discourse on issues relating to empowerment. Silverman usefully considers the types of activities that may be used as a vehicle for empowerment. She describes potential activities such as exhibit-making which can support communities to challenge stigma and provide an opportunity for groups to act as advisors or consultants. Davies (2010), in her analysis of how external partners can be involved in the co-production of exhibitions, also identifies the opportunity for partners to be involved in curatorial practices, marketing, events organisation and education programmes. Davies's ideas link to Lagerkvist (2006), Mulhearn (2008), Lynch and Alberti (2010) and Lynch (2011a) who discuss the co-production of exhibitions as a vehicle for empowerment. Andrews (interviewed as part of Mulhearn's 2008 article) states that true co-production has probably never been attempted within museums. Therefore, the extent to which communities are empowered by this activity is difficult to assess.

In reality, a variety of activities could produce empowering practices in museums, as the museum can be a focus of activities that can support people to gain the skills to negotiate power and control (Solomon 1976), or improve their quality of life and their political position within society (Wallerstein 1992), all of which form the basis of self-empowerment. Therefore, any museum project which is designed with these aims could be a vehicle for empowerment, whether it is a co-productive exhibition, an in-depth consultation to identify and dismantle barriers to access, or a programme designed to enable the community to choose key objects to be incorporated into the museum's collections to represent them. It is interesting to note that examples within the literature do not deconstruct the processes behind activities that are designed to support people to empower themselves. They also do not tend to focus on the direct benefits to community members' lives. So, given that Lynch (2011a; 2011b) identifies that communities are often engaged in what can be described as 'empowerment-lite', what would genuine empowerment look like in the museum context? In relation to this point, the literature highlights the need for communities to have a voice and gain access to decision-making. On this subject, Cornwall (2008a) states that:

being involved in a process is not equivalent to having a voice. Voice needs to be nurtured. People need to feel able to express themselves without fear of reprisals or the expectation of not being listened to or taken seriously. [...] Translating voice into influence requires more than simply effective ways of capturing what people want to say.

Of course, some groups might already be politically aware and already have the skills to be experienced lobbyists. However, Cornwall's statement identifies the importance of supporting people to develop the skills and confidence needed to

advocate for change, which is in alignment with the work of Freire (1972) and Solomon (1976), as previously discussed.

Overall, although there are some useful elements that can be derived from the literature, a clear and systematic picture of the important issues that underpin empowerment work, the processes involved in supporting people to empower themselves and the outcomes of these practices are not fully described.

Therefore, when planning the research at the Centre I had no museum-related 'blueprint' to follow. However, the emancipatory disability research principles had been developed, and these were used to inform the methodology utilised within the study, as will be described in Chapter 4. However, before moving onto the research methodology it is important to explore the issues relating to disability and museum practice, as this provides an important context in relation to understanding disability issues at The Holocaust Centre.

## **Disability and the Museum**

O'Neill succinctly sums up the broad sectoral issues in relation to disability:

Anyone who has worked in public institutions in the past twenty or thirty years has learned a great deal about disability. For some this was in response to their own commitment to improving access, for others it was a response to pressure from activists, charities and funding agencies, such as the Heritage Lottery Fund; and everyone had to comply with new legal requirements (2008, 28).

This statement is interesting, as it picks up on the issue that internal staff commitment can sometimes be the driving force behind change, and that sometimes the driving forces are external agendas. Particular challenges occur when change comes from outside the museum's walls as staff may not be ready for change or have the commitment needed to implement it. They may lack the

knowledge and skills to know how to appropriately support the needs of disabled people. The introduction of the Disability Discrimination Act 1995 (DDA) (Minister for Disabled People 1995) provided a large impetus for the sector to make improvements to disability access, as it became illegal to discriminate against a disabled person on the grounds of their disability in regard to employment and access to goods, facilities and services (Department for Education and Employment 1999). Service providers were required to make 'reasonable adjustments' to buildings and services, or provide auxiliary aids to ensure accessibility.<sup>13</sup> For example, blind visitors could gain access to the content of an exhibition through an audio tour to help them to navigate around the space and so understand the exhibition through touch. On the one hand, the DDA (1995) was hailed as 'a fundamental advance in the civil rights of disabled people' (Disability Now 1997, 1) but on the other hand it was criticised as a weak piece of controversial legislation that did not provide clear guidance for organisations (Gooding 1996). The term 'reasonable adjustments' caused the most controversy (Brindle 1996). As it is a vague term, if museums are not committed to improving access it can mean that they can implement the bare minimum of alterations to avoid prosecution. This is confirmed by the Re:source (2001) survey of provision for disabled users of museums, archives, and libraries which reported that only 4% of the museums surveyed considered themselves to be high performers in their approach to provision of disability access. Re:source also concluded that museums placed too great an emphasis on physical access, overlooking the needs of people with sensory impairments,

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<sup>13</sup> The DDA (1995) was superseded by the Equalities Act [known as the Equalities Act 2010] (Equality and Human Rights Commission 2011) which continued to place a duty on service providers and employers to tackle barriers to access and prevent unlawful discrimination against disabled people.

learning disabilities and mental health issues. Additionally, as previously stated in relation to technological barriers to access, only 1% of museums met the legal requirement for web-based accessibility standards (Petrie, King, and Hamilton 2005).<sup>14</sup> Therefore, in terms of anti-discriminatory practices and the removal of disabling barriers, this presents a disappointing picture of the sector.

However, there is a wealth of practical guidance on how to make exhibitions and services accessible for people with different impairments (Bone, McGinnis, and Weisen 1993; Groff and Gardner 1990; Nolan 1997; Landman et al. 2005).

However, Majewski and Bunch (1998), Re:source (2001) and Sandell et al. (2005) point out that when the literature discusses disability issues more broadly, it places an emphasis on physical access. Whilst it is acknowledged that access guidance is extremely important to museum staff who need to make changes to their sites and services, guidance alone cannot create holistically accessible institutions. Approaches are needed which involve disabled people in the shaping of museum practice. Charleston (1998) discusses the expression 'Nothing about us without us',<sup>15</sup> adopted by the UK disability movement to describe how issues of disability oppression cannot be changed within society if disabled people's voices are not at the heart of changes. Cited in Driedger (1989, 28) Charleston quotes Ed Roberts, one of the leading figures of the international disability rights movement, who states that 'if we have learned one thing from the civil rights movement in the US, it's that when others speak for you, you lose'. This sums up the need for disabled people to self-advocate for change, and demonstrates how if other people make decisions on their behalf

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<sup>14</sup> The Re:source (2001) and Petrie et al. (2005) surveys are the most recent to cover the museums sector.

<sup>15</sup> Charleston (1998) explains that he first heard the expression 'Nothing about us without us' in South Africa in 1993, when two of the leaders of the Disabled People South Africa (Michael Masutha and William Rowland) used it in a speech.

they will remain in a disempowered position. It places the onus on museums to involve disabled people more centrally in decision-making processes.

When thinking about the levels of access that museums involve disabled people in, Majewski and Bunch (1998) describe three levels of disability access to exhibitions in which the lowest level can be seen as access into the museum space, the second level as access to the exhibition's content and the highest level, which focuses on the representation of disabled people within the exhibition narratives. When analysing Majewski and Bunch's approach, I previously contended that there was a higher, fourth tier of access to decision-making when looking at the power relationships between museums and disabled people (Hollins 2010b), which corresponds to Arnstein's (1969) Ladder of Participation. Although many museums may consult with disabled people over their strategic developments, there is a gap in the literature in relation to museums, demonstrating that this consultation occurs at the power-sharing and decision-making levels.

I would argue that museums need to take a much more holistic approach to ensure that the needs of disabled people are met. My experience of museum practice in the UK is that museums often get elements 'right'. For example, they might have one exhibition that is more accessible than others, or a good approach to accessible marketing materials. However, what is missing in this context is a holistic approach to access issues. In Sandell, Dodd and Garland-Thomson's (2010) publication *Re-presenting Disability: Activism and Agency in the Museum* I raised the question 'What would a holistically inclusive museum experience look and feel like?' I offered the following description.

This vision would include accessibility at every step along a visiting journey from the point a disabled person inquired about the museum through to the satisfactory conclusion of their visit. It would involve the provision of an inclusive website, accessible marketing targeted at the disability press and accessible media, clear accessible signage and exhibitions which supported the needs of people with physical and sensory impairment, people with learning disabilities and mental health issues. Accessibility would extend across the whole museum site to include the building, visitor services facilities, café and toilets and disabled visitors would recognise the excellent customer service as all staff would understand the needs of this audience. From start to finish disabled people would know that this was a place for them, as the museum would clearly demonstrate this through its environment, its content, the actions of staff and the ease of the visit. Disabled people would not feel separated or segregated from their companions and would not need to engage in awkward conversations about access difficulties. Importantly, they would also see disability histories, [and] topics which affect their contemporary lives [...] represented within the museum's displays and learning programmes (Hollins 2010b, 229-230).

However, this is a picture of museum practice that I do not recognise within the contemporary UK museums sector. Weisen<sup>16</sup> (2010, 54) discusses how recent high profile museum developments have overlooked the needs of disabled people:

Billions have been spent in recent years on new museums, major extensions and refurbishments across the globe, with little or no regard paid to providing a shared experience of the collections for disabled people. The cumulative effect is discrimination on a grand scale.

This statement highlights how the DDA (1995) (Minister for Disabled People 1995) and subsequent Equalities Act (2010) (Equality and Human Rights Commission 2011) have had a limited impact on museum practice. Weisen (2008, 251) additionally states:

Access for disabled people can only be realized successfully if it becomes integrated into everything a museum does. As we begin to get a handle on existing barriers [...] new barriers are appearing such as those to virtual access. Access is an ongoing process and requires a systematic

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<sup>16</sup> Marcus Weisen is the former Health and Disability Adviser at MLA, whose post took a national strategic view of disability issues for the museum sector.

approach. Whilst we can celebrate the many recent changes, we are under no illusion that there is still a long way to go.

This demonstrates that museums have some distance to travel to ensure that disability access is embedded across their organisations. It is particularly interesting that Weisen (2008) notes how museums need to keep up with the development of new technologies which may create additional unforeseen barriers. It is intriguing to note that there is a gap in the literature in relation to the reasons that museums give for poor access as it would be beneficial to understand the institutional thinking behind the non-prioritisation of disability issues. In Sandell's (2003) analysis of the factors that prevent the museum sector from engaging in social inclusion, he cites entrenched staff attitudes, exclusive working practices, a lack of commitment, a lack of staff knowledge and skills and limited workforce diversity. Chapter 6 details whether the data parallel any of these issues in relation to changes in the Centre's staff's working practices.

In addition to the low priority that museums can place on disability access, Candlin (2003, 100) makes an important point about the way that museums misunderstand the complexities of people's impairments:

blind people are a heterogeneous group, coming from all social classes, all cultural, racial, religious and educational backgrounds. Their reasons for visiting museums and galleries almost invariably have more in common with those of the non-blind than with other blind people. Blind people go to galleries because they love Impressionism [...] because it's somewhere to take their grand-children [...] because the café is good.

Candlin highlights how people with the same impairment can have very different motivations for their visit that are not related to their impairment. This issue can also be applied within an impairment group. For example, the needs of someone

who is partially sighted and who has lost their peripheral vision will be very different to those of someone who is registered blind, and who only sees vague differences in light and shade. Therefore, museums need to develop a more sophisticated and complex understanding of how to cater to the interests and needs of disabled people. It can be argued that the coordination of this strategy alongside catering to other audiences' needs, is a practice rarely seen within the museum sector. Candlin (2003) argues that the lack of basic access provision means that blind people can only ever visit museums in a disabled capacity.

The Disability Portfolio booklets identify some important steps that can help museums navigate the complexities of how to make the museum space accessible. It advises museums to implement disability awareness training to all staff so that people across the organisation understand the needs of disabled people (Re:source 2003a). Furthermore, it advocates that museums undertake an access audit of their buildings, sites and services to identify current access barriers (Re:source 2003b), and encourages museums to make contact with local disability groups so as to involve them in consultations (Re:source 2003c). These issues will be important when considering the nature of the engagement between The Holocaust Centre and the Pioneers, and therefore will be revisited during the analysis of the data.

### ***Disability Representation in Museums***

A more developed area of the literature relates to the issues surrounding the representation of disabled people in museum collections and displays. Research conducted by the RCMG has shown that, although museums possessed a wealth of material relating to disability, it was rarely displayed in ways directly

addressing issues of disability (Dodd et al. 2004; Sandell et al. 2005). Furthermore, Dodd et al. (2006, 9) point out that interpretive materials accompanying displays of objects related to disability often portray negative stereotypes, representing disabled people 'as pitiable and pathetic, as freaks, as objects of ridicule, as a burden or as incapable'. This picture parallels the common negative stereotypes of disabled people in the media, as identified by Barnes (1992b). Delin (2002) also discusses how the absence of disabled narratives in museums contributes to disabled people's invisibility in contemporary public life, and it can be argued that this reinforces their marginal position within society. Two advancements in museum practices that have arisen from the work of the RCMG include first, the 'Rethinking Disability Representation in Museums and Galleries' action research project that set out to explore alternative ways of representing disability through collaborative and experimental approaches. As described by Dodd et al. (2008, 141): 'each of the nine projects [...] was designed to counter negative stereotypical representations and to engender support for the rights of disabled people'. Second, the recent publication *Re-presenting Disability: Activism and Agency in the Museum* (Sandell, Dodd, and Garland-Thomson 2010) explores the involvement of disabled people in shaping how disability is represented within the museum. The case studies represented are both innovative and challenging in nature and highlight the concept of activism in the museum; what Sandell and Dodd (2010, 14) refer to as 'a set of actions designed to bring about social change'. The case studies provided in this publication examine 'unsettling' practices in order to explore how disabled people have exerted an influence on the representation of disability histories and contemporary issues. This small body of literature examines the complex issues around the representation of disabled people in

museums, which will be useful context for the work of the Pioneers, especially given that one of the issues they chose to focus on was the representation of the disability history of the Holocaust through sculpture.

Overall, whilst diverse methods of engaging disabled people in procedural aspects have a place in the literature, a gap emerges in regard to an exploration of the empowerment of disabled people through their involvement with museums.

## **Conclusion**

This chapter has aimed to apply the issues of social exclusion, oppression and disability to the museum context. It has established that inequalities were built into the museum within their initial phases of development (Bennett 1995; Macdonald 1998; Witcomb 2003; Weil 2007) and that museum professionals are still trying to address this legacy today. Sandell (2003, 55) eloquently sums up the main themes that have run through this chapter:

To be more effective as agents of social inclusion, museums must seek to renegotiate the basis of their relationship with communities. Rather than developing aims and objectives internally, based on the organization's agenda and priorities, museums must learn to develop mechanisms through which communities can be empowered to take part in the decision-making process. For many, this democratisation of the museum and the resultant sharing of power, resources, skills and knowledge between museum and audience, challenges the very notion of the museum professional as 'expert'.

This statement picks up on the key themes of inclusion, anti-oppressive practices and empowerment which have threaded through this chapter.

The next chapter will explore the use of emancipatory research principles as applied to the research study, to examine whether this methodology was able to

support the Pioneers in challenging exclusionary practices at the Centre. Before moving on, however, it is important to note that the research was planned during 2005. At this time many of the ideas from key authors which have influenced this chapter were not yet in publication. Ideas about co-production (Davies 2010; Govier 2009; Simon 2010), power-sharing and radical trust with communities (Lynch and Alberti 2010; Lynch 2011a), museums' involvement in issues of empowerment (Witcomb 2007; Silverman 2010) and issues relating to activism and disability representation (Sandell, Dodd, and Garland-Thomson 2010) were not in the public realm, and so were unavailable to influence the design of the study. The main debates within the museum literature related to issues of social inclusion and pragmatic matters of disability access. Instead the research drew its influences from the academic field of disability studies, and the key ideas that underpin the research will be discussed in the next chapter. It is also worth noting, however, that the more recent museum literature has provided a useful context for the analysis of the data.

## **Chapter 4: Research Methodologies**

### **Introduction**

This chapter explores the approach taken to the research and the philosophies and principles that underpinned its planning. It discusses the historic exclusion of disabled people from the research process and the principles that shaped the development of the new emancipatory disability research paradigm developed within the field of disability studies (Hunt 1981; Oliver 1990; 1992; Abberley 1992; Zarb 1992). Given this context, the rationale behind the research questions is examined along with the selection of the case study. The context of The Holocaust Centre and the Pioneers group is introduced in more detail, and the influence that all of these elements had on the choice of methodologies and the methods is discussed to give the context for the research design. The ethical issues involved in conducting disability research are also examined along with my positionality as a researcher. The complications involved in analysing a large data set are discussed, as although there are benefits to collating a wealth of data (as it supports a greater depth of analysis), there are challenges to ensuring that the significant issues, patterns and pieces of data 'emerge' from the data pool. Finally, the approach taken to the analysis is investigated.

### **The Historic Exclusion of Disabled People from the Research Process**

In the early 1990s, following the development of the social model, the emerging field of disability studies started to critically analyse the traditions and protocols

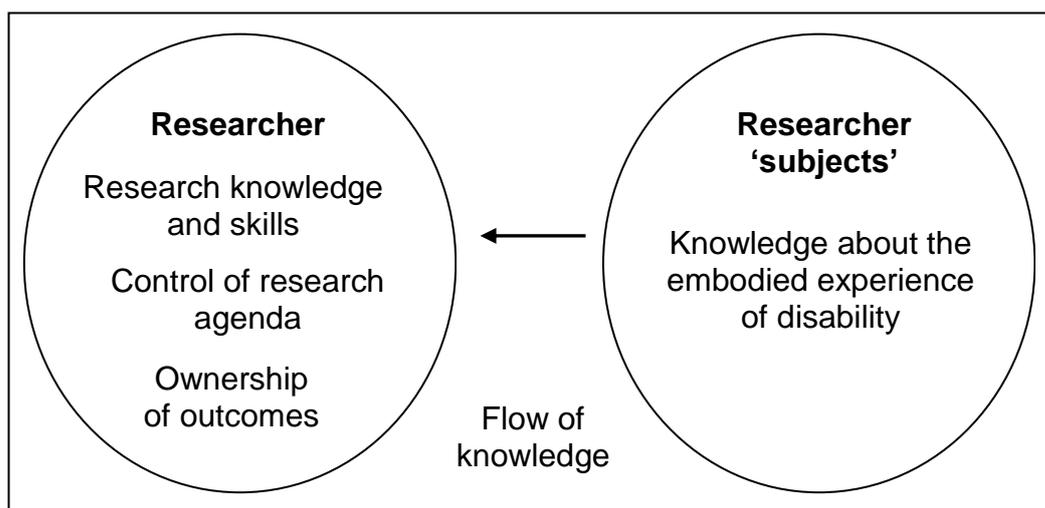
of the research process. Leading researchers in the field of disability studies argued that research processes had historically excluded disabled people (Hunt 1981; Oliver 1990; 1992; Abberley 1992; Barnes 1992a; Zarb 1992). They examined the research methodologies developed within the scientific and social sciences traditions, and concluded that these approaches were contributing to the exclusion of disabled people. As explained by Kitchin (2000, 26):

Often cited within these arguments is the critique of Hunt (1981) who describes the experiences of being a 'victim of research'. He details how, as a resident of Le Court Cheshire Home, he and other residents became disillusioned with "unbiased social scientists" who followed their own agenda and ignored the views of the people they consulted.

The disabled residents felt their views had been misappropriated and that knowledge had been 'mined' without benefit to them (Kitchin 2000).

Hunt (1981) discusses the disempowering experience of being a 'disabled subject' of research. At the centre of this type of research are power inequalities: the researcher is seen as the 'expert', the gatekeeper to knowledge, whereas disabled people play a passive role, receiving no tangible benefits from their involvement. Kitchin asserts that this type of research compounds 'the oppression of disabled respondents through exploitation for academic gain' (2000, 45). Looking back on disability research from the 1950s onwards, Barnes (2001; 2009) does note a few exceptions to this picture, highlighting projects where researchers showed more political sensitivity to issues of impairment. Overall, however, in this researcher-oriented practice the main beneficiary of research is the researcher, who advances their career by 'using' the disabled people's views to answer their agenda. Following this ideas, the flow of knowledge about an issue is in one direction towards the researcher (see Figure

5), as under this approach the research does not aim to enrich disabled people's lives or challenge their exclusion within society. The researcher is in control of the agenda, how the research is conducted, how it is interpreted and the outcomes that emerge, both in terms of how the study is published and how it is presented to the wider academic community.



**Figure 5: 'Traditional' social sciences research practice (after Hollins 2010b, 231)**

## **Development of the Emancipatory Disability Research Paradigm**

'The term paradigm has been used to refer to the dominant framework in which the research takes place' (Hammond and Wellington 2013, 116). Crotty (1998) provides the most comprehensive discussion about potential paradigms that researchers can adopt, exploring positivism, interpretivism, critical inquiry, feminism and postmodernist paradigms. However, in the context of the field of disability studies the main debate focuses on critiques of the positivist and interpretivist paradigms; therefore, rather than defining and debating all of the above terms the next section will focus in on analysis of these specific paradigms.

Oliver (1992) refers to positivism and interpretivism as the 'traditional' research paradigms within the social sciences. According to Oliver (1992), positivism has long been the dominant paradigm in social sciences research and is based on a series of assumptions about the social world, which he summarises as the belief that the social world can be researched from a realist epistemology. This school of thought states that social reality exists independently of an individual's beliefs, and that it can be studied in the same way as the natural world (Gray 2004; Denscombe 2010). From this perspective, research is objectively conducted and is values-free (Oliver 1992). However, Oliver questions whether research about disabled people can actually be conducted in an apolitical, values-free framework. Although he states that research within the socially contextualised interpretivist paradigm is a step forward, as it sees the social world as a more complex value-laden place, from a disability perspective he argues that under this framework:

research still has a relatively small group of powerful experts doing work on a larger number of relatively powerless research subjects. To put the matter succinctly, interpretive research is just as alienating as positivist research because what might be called "the social relations of research production" have not changed one iota (Oliver 1992, 106).

His argument focuses on the power inequalities that are present between the researcher and research subjects in this mode of research production. Oliver concludes that both the positivist and interpretivist paradigms have historically reinforced the medical model, and so calls for the development of a new paradigm. Oliver applies ideas about emancipatory research being developed within the field of women's studies to the disability context, drawing in particular on Lather (1987), who describes emancipatory research as exploring the lived experiences of oppressed groups within society. Lather explores how

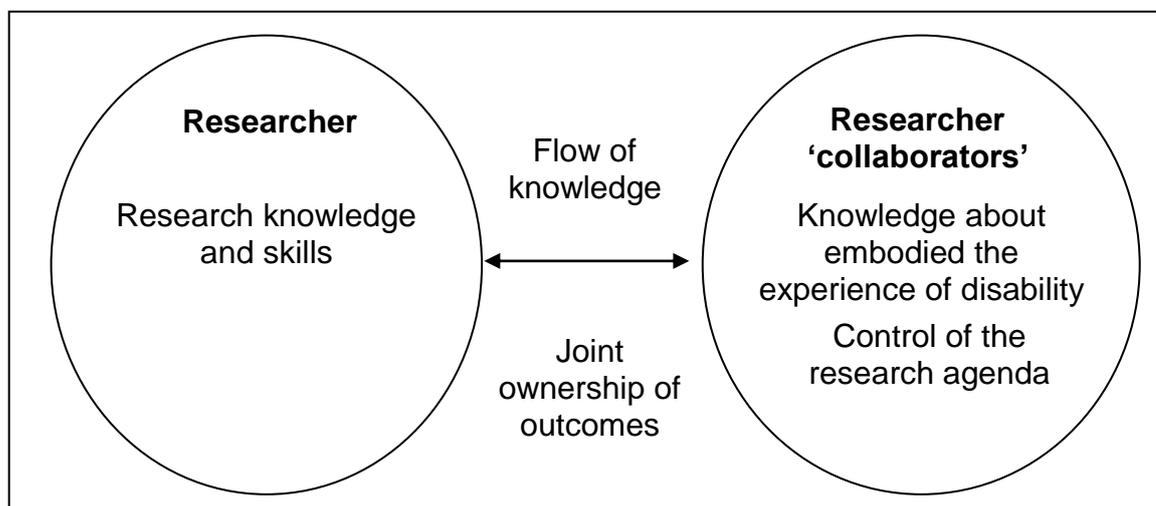
emancipatory research focuses on the relationship between ‘the researcher and researched’ so that both are changed by the process. Therefore, Oliver’s ideas about research can be situated within a wider field of emancipatory research (as described in Truman, Mertnes, and Humphries (2000)) that aims to challenge oppression through research.

### ***The New Paradigm: Emancipatory Disability Research***

In response to the exclusion of disabled people from the research process, researchers from within the field of disability studies (Barnes 1992a; Oliver 1992; Zarb 1992) started to develop the new emancipatory disability research paradigm. This paradigm has the social model of disability at its core (Stone and Priestley 1996; Barnes 2001), and just as the social model aims to place the onus on society to remove disabling barriers, emancipatory disability research intends to remove disabling barriers from the research process (Oliver 1992). It follows a set of underlying principles that shape the way that the research is planned, implemented, analysed and disseminated and places disabled people’s voices at the Centre of the process (Zarb, 1992; Stone and Priestley, 1996; Kitchin, 2000). This paradigm has generally been associated with qualitative rather than quantitative data collection (Barnes and Sheldon 2007), with a set of key principles underpinning the chosen methodologies and methods. The issue of whether quantitative or qualitative research methods will be deployed in this study will be explored more fully later in this chapter. However, at this stage the discussion will focus on the development of emancipatory research.

Oliver (1992) indicates that these key principles are reciprocity, empowerment and gain, created through a dialogue with disabled people in order to lead to

personal and social transformation. In this model there is a shift in the power relationship between the researcher and disabled people (see Figure 6) with mutual outcomes being negotiated between the parties.



**Figure 6: Emancipatory disability research paradigm (Hollins 2010a, 233)**

Through an examination of the disability literature other authors have built on Oliver (1992) to create the following set of principles – the ones used in this study – although there is no consensus on which principles are most important (and not all authors highlight the full set of principles in their work).

**Empowerment:** Oliver (1992) draws on Freire (1972) when discussing empowerment. He states that empowerment cannot be 'bestowed' on one group by another. Disabled people need to be supported to empower themselves, and research can be one method to achieve this aim. Mercer (2004, 6-7) states that the 'self-empowerment of disabled people might take several forms: documenting social barriers and oppression, re-evaluating perceptions of disability, and taking political action'. Oliver (1992) draws on Lather (1991) to state that self-empowerment might include individual self-assertion or the

psychological experience of feeling powerful. This study aimed to support the Pioneers to empower themselves through the implementation of the aims that they chose as a focus for the research.

**Reciprocity:** Oliver (1992) talks about the development of a reciprocal relationship between the researcher and the people involved in the research, where together they build a relationship based on trust and respect. Barnes (1992a, 122) states that researchers need to establish a dialogue with disabled people 'in order to facilitate the latter's empowerment. To do this, researchers must learn how to put their knowledge and skills at the disposal of disabled people'. Swain (1995) talks about the researcher and disabled people developing a partnership to focus upon mutually beneficial outcomes. This study aimed to develop a collaborative relationship between the Pioneers and myself as the researcher, with their embodied knowledge being placed on an equal footing with my knowledge about the research process, so that we could learn from one another.

**Gain:** Stone and Priestly (1996) state that research should only be undertaken when it is of practical benefit to the self-empowerment of disabled people. Research should be used as a tool for improving the lives of disabled people, and they should directly benefit from their involvement (Barnes 2001; 2003a; Barnes and Sheldon 2007). This principle is implemented so as to overturn the power dynamic that occurs in many types of social sciences research where the principle beneficiary of the research is the researcher (Oliver, 1999; Kitchin, 2000). Similarly, this study intended to directly benefit the Pioneers and make a difference to their lives.

**Involvement of disabled people in the research process:** There should be greater opportunities for disabled people to be researchers, either as primary or collaborative researchers. Although I chose the focus of the study and the research methodologies, the Pioneers were offered the opportunity to be involved in the collection of data and its analysis and dissemination. Also important in terms of their involvement, was that the Pioneers were supported to take control of the research agenda and decide on the direction of the action research (as recommended by Kitchin 2000).

**Reflexivity and Reflectivity:** Chappell (2000) states that researchers must adopt a more reflexive approach to their work. They should be responsive to the needs and issues that arise during the research process, and be willing to improve or modify their approach to ensure that disabled people are fully able to participate. Bewley and Glendinning (1994) focus on the practical issues of ensuring that research is inclusive, stating that meetings may need to be held at different times of day so that they can fit with disabled people's schedules. They also state that 'attention to simple factors such as the proximity of accessible toilets, loop systems and signers' can be important to support disabled people's involvement (Bewley and Glendinning 1994, 312). Therefore, throughout the process the intention was to adapt the approaches so that the Pioneers' needs were fully supported.

**Politically motivated research and the loss of neutrality and objectivity:** As stated by Oliver (1992), research with disabled people is a political act as it aims to support an oppressed group to challenge power inequalities, both in the research process and in wider society. Barnes (2003a) argues that social-sciences research cannot be conducted from an objective position, as it is

conducted by researchers who are affected by their personal experiences, and whose interpretations of the world are always politically, socially and culturally situated. Barnes calls for the need to erode the 'myth' of the independent, objective researcher, stating that: 'If disability research is about researching oppression [...] then researchers should not be professing "mythical independence" to disabled people, but joining with them in their struggles to confront and overcome this oppression' (Barnes 1996b, 110). The research was thus conducted with the intention to challenge power inequalities in the research process and oppressive exclusionary practices at the Centre.

**Control of the research agenda:** Barnes (2001, 5) asserts that 'disabled people and their organisations, rather than professional academics and researchers, should have control of the research process [and] that this control should include both funding and the research agenda'. However, this piece of PhD research was not commissioned or funded by a disability organisation, meaning that this principle could not be applied. However, in this study the Pioneers were supported to take charge of the research agenda. Barton (2005) states that disabled people should be in control of the planning, implementation and dissemination of the research. However, Mercer (2004, 11) points out that 'not [...] all disabled people have the time or inclination to take over control of the research production'. Swain (1995) highlights the need to train disabled people in research processes so that they are able to involve themselves more fully. Although I initially decided on the case study and the research methodologies utilised to gather data, the Pioneers were then supported to take control of the research agenda, once the fieldwork commenced.

**Accountability:** Barnes states that ‘accountability is a major consideration for all those striving to do emancipatory disability research’ (2003a, 7), and that by involving disabled people throughout the process the researcher can stay accountable for the way that they conduct the study. Hence, the Pioneers were given the opportunity to be involved at every stage. However, as will be discussed in Chapter 5, they were not interested in getting involved in the data collection, analysis or dissemination process.

However, Margaret Clement was interested in supporting the analysis of the data and was involved at three stages. In the early stage of analysis she viewed and commented on a summary of each of the Pioneers’ sessions that was created from a combination of the transcripts, field notes and note-takers notes. Her views were sought on whether my interpretation of the session content was a fair representation of the Pioneers work. She was also involved at the draft stage of creating the analysis, to again comment on whether the analysis was a fair representation of the project. Finally, she read and commented on the finished thesis and her comments can be found in Chapter 6. Therefore, efforts were made to ensure that the thesis was accountable to the group via Margaret, and discussions are currently underway about how the findings can be disseminated in a way which benefits the Disability Support Team and their continuing work with the Pioneers’ Forum.

Overall, these eight principles shaped the way that the research was planned, implemented and analysed. In Chapter 5 these principles will be revisited in analysing the extent to which they were followed during the study.

### *Critiques of the Emancipatory Disability Research Paradigm*

A variety of authors have questioned whether emancipatory research is achievable. Oliver (1997), for instances, asks if it is an 'achievable goal' or an 'impossible dream', and Barnes (2001) indicates that at times it has been an aspiration rather than a reality. A search through the disability literature does not uncover examples of research projects which openly claim to be fully emancipatory in nature. However, examples can be found where researchers have aimed to follow some of the principles. For example, Bennett's (2002) paper 'Disabled by Design' describes the author's attempts to engage in a user-led design/research process, and she analyses whether the research was able to meet the six emancipatory principles outlined by Stone and Priestley (1996).<sup>17</sup> Similarly, Petersen (2011) tried to follow Oliver's (1992) three principles of reciprocity, empowerment and gain to explore the relations between participants and the researcher.

Shakespeare (1996b, 118) questions the realities of engaging in emancipatory research when he states: 'I have major reservations with the concept of emancipatory research, even while admiring the motivation and commitment of those engaged in it. I am cynical about the possibility of research achieving major change, whether it be radical and emancipatory, or traditional social policy research'. Oliver (1997) raises an additional concern: that it is difficult to locate the point at which emancipation takes place, as the effects of research might manifest themselves long after the project is over. Therefore, an important part

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<sup>17</sup> Stone and Priestley's (1984) principles involved: the researcher needing to surrender objectivity, the research needing to benefit disabled people, disabled people being in control of the research agenda, for the social model to underpin the research, for disabled people's impairments to not be overlooked and for disabled people's voices to be central to research studies.

of the analysis in Chapter 6 will focus on the outcomes of the research and whether these outcomes support the Pioneers' self-empowerment. As discussed in Chapter 1, to date there have been no documented pieces of emancipatory disability research occurring in a museum context.

Overall, there is a wide debate within the disability literature about what constitutes emancipatory disability research and whether it is an achievable paradigm to implement. Following on from this, the next section will explain how the emancipatory principles and the particularities of the case study shaped the development of the research questions.

## **Primary Research Question**

The overarching research question is:

**How can disabled people be empowered to influence decision-making in museums?**

Hence, the research attempts to apply emancipatory principles to the museum context. It also involves an exploration of the power inequalities that can occur between a marginalised community and museums as institutions. As discussed in the introductory chapter, although the central case study focuses on a Holocaust museum, this piece of research could have been undertaken in any type of museum, as it focuses on disabled people's right to access culture. As previously stated, it can be argued that museums have been one of the key cultural institutions that have contributed to disabled people's marginalisation, and this study explores whether it is possible to challenge inequalities through the use of emancipatory principles.

## ***Secondary Research Questions***

The secondary research questions that flow from this overarching question can be broken down into two categories. First, as outlined in the previous section, one aim of the research was to explore what is actually involved in undertaking emancipatory disability research. Second, it was intended to unpick the outcomes of research for the Pioneers, the youth workers, myself as the researcher, the Centre's staff and the organisation. Therefore, the secondary research questions can be described as follows:

Aims in relation to the process of undertaking the research:

- To what extent can the use of emancipatory research principles enable The Holocaust Centre and disabled people to work together to challenge exclusionary practices and barriers to access?
- What factors are important when supporting young disabled people to be involved in emancipatory disability research and to take a lead role in the research process?

These questions were designed to uncover the realities of undertaking research 'in the real world', as described by Gray (2004), who discusses the challenges of undertaking applied research.

Aims in relation to the outcomes of the research:

As described by Denscombe (2010) it is important to consider the anticipated outcomes of research as part of the planning process. The idea behind this study was to hand over decision-making to the Pioneers and, therefore, the

specific outputs of the research reflected their choices. However, some general issues that arose from undertaking emancipatory research can be considered:

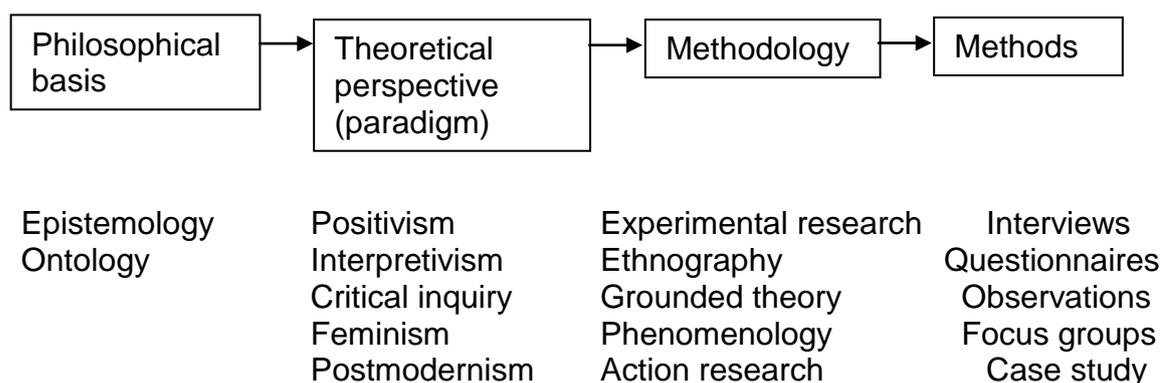
- Did the research support the young disabled people to empower themselves?
- What were the benefits of their involvement in the research?
- Did the approach of handing over decision-making within the research process have an impact on the museum?
- What impact did the research have on The Holocaust Centre and its staff, the youth workers and me as the researcher?

This set of questions explores the outcomes for all parties involved. However, there is an important distinction to be made between the research supporting the Pioneers' capacity to take control of the research agenda and decision-making within the research process, and the Pioneers having access to decision-making within the museum. These are two separate but intersecting issues. The research project aimed to support the Pioneers to make informed decisions so that they could take control of the research agenda. Depending on what the Pioneers chose to work on, this might have entailed challenging decision-making at a senior level in the Centre, or it might have focused on more pragmatic issues. The analysis in chapters 5 and 6 will explore whether access to decision-making in the museum became part of the Pioneers' agenda.

## **Elements of a Research Project**

Summarised in Figure 7, Crotty (1998) states that there are four elements involved in the planning of research projects. However, he cautions that these

are not a 'mix and match' set of options, and states that there needs to be a rationale that underpins all the choices. Hence, the decisions that were made about the way the research was designed flowed from the philosophical basis of the research.



**Figure 7: Relationship between philosophical, theoretical and methodological perspectives and research methods (Crotty 1998, 4)**

Denscombe (2010, 117) explains why it is important to have a sound philosophical foundation for any research, as 'it is possible to approach the social world from different perspectives and to see things differently depending upon the philosophical position that is taken'. With disability research it is clear that the assumptions behind the study are important. If the research were conducted from a medicalised perspective, the emphasis would be very different than if it were conducted it from a social model perspective.

### ***Epistemological and Ontological Basis of the Research***

The two elements involved in the philosophical basis of a piece of research are 'epistemology' and 'ontology' (Williams and May 1996; Crotty 1998; Gray 2004;

Hammond and Wellington 2013). Denscombe (2010, 119) describes epistemology as 'the ways that humans create their knowledge about the social world', and that this 'involves philosophical debates about the bases on which we can claim to have knowledge of social reality'. Following Priestley (1997), Kitchin (2000) and Mercer (2004), who discuss epistemology in relation to disability research, the epistemological basis of this thesis is the social model of disability. This perspective was chosen for the way it defines how disability is viewed in the social world, in which disability is socially constructed, and therefore barriers to access in the research process and in the museum context will be challenged.

As discussed by Denscombe (2010) and Hammond and Wellington (2013), the issue of ontology is intertwined with epistemology, and one cannot really be discussed without the other. Denscombe (2010, 118) states that ontology is 'the nature of social phenomena and the beliefs that researchers hold about the nature of social reality'. In terms of this study, the ontological position is that the reality for disabled people is created through an interplay between their impairment and the world around them. The ontology is therefore aligned with the social model as disability can be framed in terms of social oppression.

## **Background to the Research Methodologies and Methods**

Before embarking on an explanation of the specific methodologies and methods deployed in this study, it is worth taking a moment to explore whether the use of quantitative or qualitative methods better supported this piece of emancipatory research. Quantitative research methods refer to the systematic empirical investigation of social phenomena through the gathering of numerical data

(Denscombe 1998; Creswell 2003). The researcher begins with a hypothesis and can undertake various research methods, such as surveys or experiments, to test their theory (Creswell 2003). The data set collected tends to be large as the researcher is looking for trends and patterns that are statistically viable (Denscombe 1998). Qualitative research methods lend themselves to the in-depth investigation of complex social phenomena (Hammond and Wellington 2013), and data is gathered through various methods such as case studies and interviews (Denscombe 1998). However, in contrast to the numerical approach with quantitative methods, qualitative data focuses on gathering people's written or spoken words, as a means to uncovering their thoughts and behaviours.

In the context of this study's primary and secondary research questions, a qualitative approach was more suited to an exploration of complex issues such as empowerment, decision-making and the social interactions involved in challenging exclusionary practices within the museum space. These complex issues were played out through social relationships, and the nuances of them were more thoroughly uncovered through an in-depth case study approach, rather than a larger scale study that aimed to explore trends within numerical data.

In the next section the suitability of case study research will be explored in more detail. The case study at the heart of the research will also be introduced, as in order to understand how the specific research methodologies and methods were chosen, it is first important to understand the context of the case study. It is also important to discuss why the Centre and the Pioneers became involved with the study, as the particularities of these two elements had a large influence on the methodologies and methods that were chosen.

### ***Case Study Research***

As described by Denscombe (1998), case study research focuses like a spotlight on an individual incidence, in contrast to large-scale studies where the researcher has a wider lens. The advantage of the narrow field of view is that it enables the researcher to explore a particular phenomenon in an in-depth way and gather a 'rich' set of data (O'Leary 2004). It also provides a clear boundary for the research, and allows the researcher to employ multiple methods of data collection (Denscombe 1998). This means that the data sources can be triangulated. Hammond and Wellington (2013) discuss the benefits of triangulation, stating that it allows different data sources to be compared against one another to add validity to arguments or a comparison to be made between different perspectives. In the context of this thesis, a case study approach allowed an exploration of the research questions from the perspective of the Pioneers, youth workers, Centre staff and the researcher.

### ***Case Study Museum: The Holocaust Centre***

The Centre is an independent museum and educational centre, and was established to honour the memory of the victims of the Holocaust (THC 2006). As an organisation it aims to 'challenge anti-Semitism, racism and other forms of exclusion through teaching the lessons of the Holocaust. Since opening in 1995, the Centre has played a pioneering role in the development of Holocaust education' (THC 2007b). In the publication *Making Memory: Creating Britain's First Holocaust Centre*, Stephen Smith (2002), one of the founders of the Centre, describes how his family initially created a study room at the Christian conference and retreat centre that they ran in Laxton, Nottinghamshire. Smith

explains how his family was compelled to create the Centre in response to visiting Yad Vashem, the Holocaust Memorial Museum in Jerusalem, during a family holiday. Smith (2002, 30) describes their visit: 'That day at Yad Vashem we set out to try and understand the challenges of the Holocaust for us [...] Our question was, quite simply "What should the challenge of the Holocaust mean to us?". They raised this question as their family was not Jewish, and therefore the Holocaust was not part of their family history. He explained further:

I remember so distinctly walking around those darkened galleries. I don't remember seeing the perpetrators, but the faces of the victims remained with me. I don't remember absorbing what was done and how, but I registered clearly to whom it was done – and it made no sense at all. And then the questions started to boil inside me. Why? Why did they do it? How could they do it? At times I was angry, at times I was sad, but most of all I was simply confused. [...] Confronting the Holocaust at a place like Yad Vashem is an immensely moving and emotional experience (Smith 2002, 30).

For most people the response to this may have been self-reflection and a greater insight into what humanity was capable of. However, for the Smith family it set in motion a chain of events that would see them establishing a Holocaust centre on the grounds of their rural Nottinghamshire home. In the mid-1990s, Smith (2002) described how the Holocaust was still not widely discussed in the public sphere, and explained how his family decided to respond in a practical way. Created by Marina, Stephen and James Smith (mother and two sons), the Centre included a memorial hall, a Holocaust exhibition, memorial gardens and visitor facilities (reception, café, shop and toilets).

### *The Memorial Hall and the Education Programme*

At the commencement of the fieldwork the Centre welcomed an average of 20,000 visitors a year, the majority of whom were secondary school students

(THC 2005b). Its education programme was delivered with a memorial hall that incorporates stained glass commissioned by survivors (Smith 2002) (see figures 8 and 9). The secondary school students who visited the Centre came for a programme, which involved visiting the exhibition, meeting a survivor of the Holocaust and reflecting on their experiences in the memorial gardens (see Figure 10).



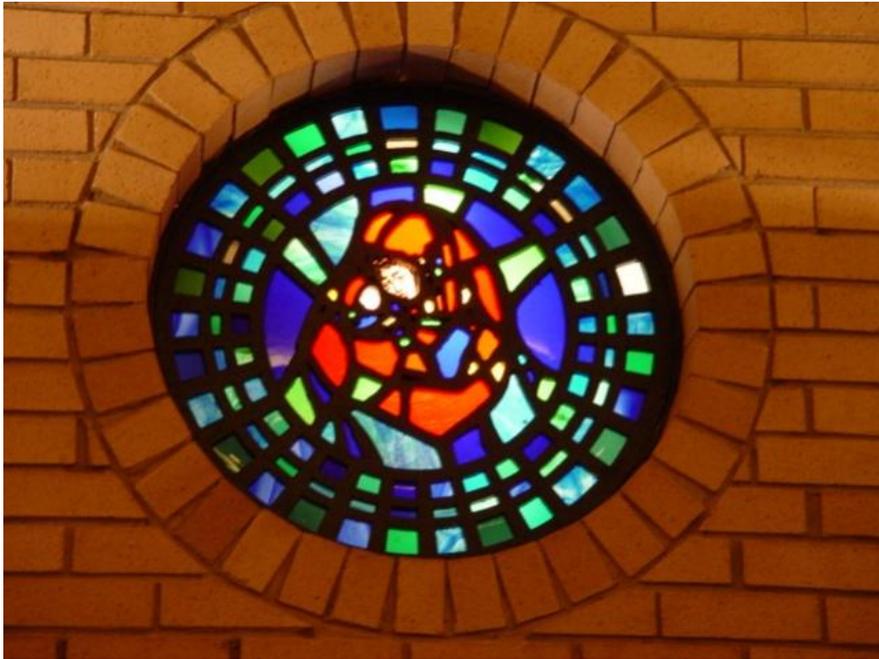
**Figure 8: View of the memorial hall from the grounds**

As stated on the Centre's website the education programme aims to promote:

an understanding of the roots of discrimination and prejudice, and the development of ethical values. [...] The Centre uses the history of genocide as a model of how society can break down, and emphasises how current and future generations must carefully examine and learn from these tragedies. The Centre promotes respect for human rights,

equal opportunities and good citizenship, which has greater resonance than ever in our culturally diverse society (THC 2012a).

It therefore not only aims to explore the history of the Holocaust, but also to examine the issues that are relevant to our contemporary society.



**Figure 9: The memorial hall: 'Mother and Child' stained glass**



**Figure 10: Trudi Levi, Holocaust survivor, talking about her life to secondary school students (photograph courtesy of The Holocaust Centre)**

## *The Holocaust Exhibition*

The exhibition follows a fairly 'traditional' Holocaust narrative as seen in many Holocaust museums, exploring the rise of the Nazi Party and the development of the Final Solution,<sup>18</sup> which led to the Jewish people's confinement in ghettos, and to their industrialised mass murder in death camps (see figures 11 and 12).



**Figure 11: Display depicting the rise of anti-Semitism under the Nazis**

The exhibition emphasises first-hand accounts of survivors' stories through written and video testimonies. It aims to turn the overwhelming statistics involved with the Holocaust into stories about people, helping visitors to empathise with the people who were affected by these events. The chronological narrative predominantly focuses on the Jewish community's

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<sup>18</sup> The Nazi Party used the term 'Final Solution' to refer to their plan to eradicate the whole of the Jewish population.



**Figure 12: Death camps barracks display**



**Figure 13: Original 'Star of David' which was sewn on Jewish people's clothes to identify them as Jewish**

experiences, although other communities such as ethnic minorities, disabled people and Roma and Sinti traveller communities<sup>19</sup> are briefly mentioned.

As can be seen from figures 11 and 12, the idea behind the design (as described in THC 2005b) is to create a series of 'sets' which provide a backdrop and context to the narrative. In 1995, the Centre did not have a collection, so there are only a few original objects in the exhibition (for an example see Figure 13). Text panels and photographs create the majority of the content, which presents a 'book on the wall' approach to interpretation (see Figure 14).



**Figure 14: Display about Jewish people who have made major contributions to the arts, science and literature**

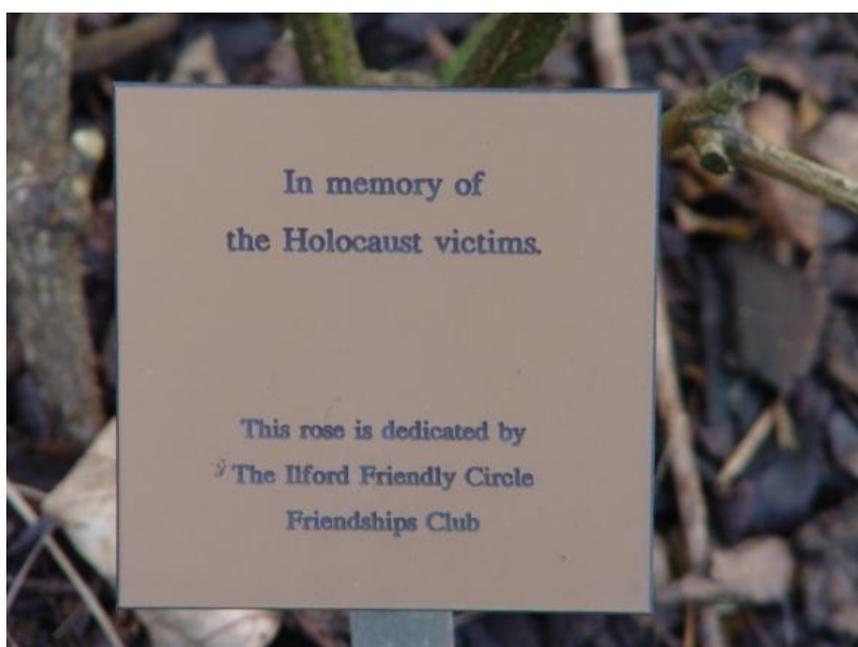
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<sup>19</sup> The Roma and Sinti are different 'branches' of the central European Gypsy community.

This mode of interpretation was not uncommon in the mid-1990s and the exhibition had not been updated since it opened in 1995.

### *Memorial Gardens*

The memorial gardens are set in two acres of grounds surrounding the Centre (THC 2012c). They provide an important counterpoint to the exhibition, encouraging visitors to walk in the peaceful grounds and reflect on their experiences of visiting the Centre. Dedicated by individuals, families and organisations, the roses in the gardens memorialise families and communities who were killed during the Holocaust (see Figure 15). Visitors can wander around the gardens and read the plaques that accompany each rose. Amongst the roses there are sculptures commissioned by people who survived the Holocaust, by their families, or by artists who have a connection with this history (see Figure 16).



**Figure 15: A plaque in the rose garden**



**Figure 16: 'Brothers in Hiding' a sculpture commissioned by Simon Winston, whose family went into hiding during the Holocaust**

### ***Disability Access and Representation***

As identified in the Centre's Access Plan (Hollins 2005), there were significant and numerous physical, sensory and intellectual access issues built into the Centre. As the research questions for this study do not focus on a comprehensive analysis of the barriers to access, I will not detail all of the 68 issues identified in the plan. However, to give some idea of the extent of the access barriers: although the Centre had an accessible toilet, apart from this there were barriers built into every feature and facility on the site. These ranged from issues such as the 'book on the wall' interpretive approach in the main exhibition, which restricted access to the exhibition content for people with

visual, hearing or intellectual impairments (see Figure 17), through to the stair lift in the main exhibition that had been installed at the end so that people with physical impairments needed to travel through the whole exhibition in reverse in order to find the exhibition's start. This stair lift was permanently broken, and even when it had worked, due to the way it had been installed it did not allow users to travel all the way down to the bottom of the stairs (see figures 18 and 19).



**Figure 17: Display created using small plaques and photographs**

Drawing on Hollins (2010b), it can be argued that the complex range of access issues built into the Centre demonstrated that the staff who worked on its development lacked the knowledge and skills needed to build accessible features into the designs. Furthermore, at the early stages in the organisation's



**Figures 18 and 19: Main exhibition stair lift. Figure 18 (left) shows the length of the stair lift. Figure 19 (right) shows how the stair lift ends before the last three steps of the stairs**

development disability access was not one of its priorities. James Smith, Chief Executive, reflected on these issues in his interview:

When we opened the place we weren't thinking of access issues as we should have done. We made some gestures like putting a loop system in which didn't work very well. Yeah the disabled lift – that went down, most of the way down some steps. [...] We were always running on a shoe string budget, and we said that we would address it as soon as we could [...] but that went on for far too many years.

In addition to the range of physical, sensory and intellectual barriers that were built into the site, the disability history of the Holocaust was largely overlooked in the Centre's exhibition and programmes. At this stage it is worth taking a moment to explain the disability history of the Holocaust, as it can be described as a 'hidden history' (Hollins 2010c). As Evans (2001, 1) states:

In spite of greatly heightened interest in the Holocaust in recent years, silence has surrounded the mass atrocities inflicted on men, women and children with disabilities under the Nazi regime. The vicious and systemic persecution of people with disabilities during the Nazi era has been overlooked and greatly underestimated in historical research and our collective remembrance of the Holocaust.

Estimates vary on how many people were killed during the Holocaust, although the common consensus seems to be around 11 million, with the largest grouping being six million Jewish people. Of the five million non-Jewish victims an estimated 500,000 were disabled people (Makoff 2011),<sup>20</sup> and a further estimated 700,000 disabled people were sterilised as part of the Nazis' eugenics programme<sup>21</sup> (Evans 2001; 2004; Shakespeare 2007). Hitler was obsessed with the idea of a genetically 'superior' Aryan race, and believed that any groups in society who possessed 'inferior' genes should be exterminated to protect the 'purity' of the gene pool. This included Jewish people, other ethnic minority groups, homosexuals, Roma and Sinti traveller communities and disabled people (Evans 2001). The Nazis adapted the eugenic ideology that was widespread across Europe and North America (Mitchell and Snyder 2003), arguing that allowing disabled people to live and have children weakened society's ability to function efficiently, placing an unnecessary economic burden on society (Proctor 1988). Initially, laws were implemented that led to the sterilisation of 700,000 disabled people in Germany (Shakespeare 2007). However, in 1939, under the cloak of war, 'sterilization quickly turned to murder'

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<sup>20</sup> Most estimates state that around 25,000 disabled people were killed in the Holocaust. However, a further 220,000 victims were found in a mass grave in the grounds of an Austrian psychiatric hospital in 2011, which gives an indication that the overall figure is higher than previously estimated.

<sup>21</sup> The eugenic movement was based on 'social Darwinist' views that the evolutionary concepts of 'natural struggles' and the 'survival of the fittest' could be applied to human societies, and that 'weaker' genes should therefore be removed from the gene pool.

(Evans 2001, 9) with the instigation of the secret 'T4 Programme'.<sup>22</sup> Six death camps, called 'euthanasia centres', were set up across Germany and Austria (Proctor 1988; Friedlander 1995). Disabled people were the first community to be killed en masse by the Nazis, and a direct line can be traced from the use of gas chambers at the euthanasia centres to the development of the industrial-sized killing centres such as Auschwitz (Lifton 1986; Friedlander 1995). As described by Evans (2001; 2004) and Mitchell and Snyder (2003), the history of disabled people's during the Holocaust has been largely overlooked in the academic literature and public remembrances, including museums (Hollins 2010c). At the Centre there are few references to disabled people's experiences in the main exhibition, and those that exist are mainly located in one dark corner behind a door (see Figure 20).



**Figure 20: The disability section in the main exhibition**

<sup>22</sup> The 'T4 programme' was named after the address of the programme's headquarters at Tiergartenstrasse 4 in Berlin.

In addition to this, the Centre's programmes did not, at the time of the research, highlight this history and predominantly focused on the Jewish community's experiences. Evans (2004) argues that it is important to remember the history of disability in the Holocaust as prejudice about disabled people's is still commonplace in our contemporary society. At the Centre, even within narratives written specifically about exclusion, disabled people histories were being marginalised.

However, it must be acknowledged that the exhibition contains only limited space for a broad interpretation of the Holocaust, and in 1995 when it was created, the academic and public conception and remembrances of the Holocaust focused mainly on the Jewish community. However, in the past 20 years academic and public discourses about this history have moved on to include a wider diversity of communities' experiences (Lautmann 1981; Berenbaum 1990; Evans 2001; 2004; Pine 2008; Ursprung 2011). Therefore, it could be argued that the Centre needed to address the underrepresentation of disabled people's narratives, alongside offering an improved approach to the representation of LGBT, ethnic minority and Roma and Sinti Traveller communities' experiences, along with the histories of groups who were persecuted for religious or political reasons.

Therefore, overall disabled people faced a series of barriers to access which prevented them from experiencing the Centre in the same way as other visitors, in addition to the underrepresentation of this disability history.

### ***Selection of the Case Study Museum***

Initially, four case study sites were considered in order to explore the process of undertaking emancipatory research in different museum contexts. However, when investigating what was involved in implementing these principles it became apparent that it was preferable to concentrate on one case study, to allow for an in-depth exploration of the research questions. During the planning phase of the research, I took up the post of part-time Access Officer for the Centre. The advantages and disadvantages of conducting an investigation into the professional practices of my workplace were considered. Blaxter, Hughes and Tight (2010) explain the advantage of being an 'insider', which allows for the level of access required for the case study to be more easily negotiated with senior management. As discussed in Denscombe (1998), this case study could be described as a 'test-site' to allow a particular approach to be 'tried out' in a real life situation. This approach therefore involved some level of risk for the Centre, as the outcomes of the research were not guaranteed.

The disadvantages of workplace research, as described by Blaxter, Hughes and Tight (2010), involve the complexities that the insider position creates in terms of the dual relationship of researcher and work colleague. They also state that it can be easy to overlook significant issues in familiar situations, and in this respect it can often be easier for the researcher to investigate unfamiliar surroundings.

At this point it is worth taking a moment to provide context for my access role, as the initial position that I occupied in the organisation had a large impact on the approach taken to improve access issues. The Centre's management had clearly identified that there were access barriers and had articulated its

commitment to improving access in its 2004-2010 business plan (THC 2005b). As the business plan described, the funding for the access post came from the Heritage Lottery Fund grant for *The Journey* exhibition. The plan indicated that the key elements of the access post were:

- The development and implementation of strategies to ensure that the Centre was physically accessible.
- The implementation of an access audit to identify barriers, and work to remove physical barriers where practicable.
- Work with the Centre's Education Officer to ensure that the education programmes meet the needs of pupils with learning impairments.
- Improvements to the accessibility of the Centre's website.
- Engagement with underrepresented groups in new developments.

These priorities are interesting on a number of levels, as the plan only mentions physical and intellectual barriers within two particular contexts – site and website improvements – and there is no expectation that the post holder would work with the whole staff. However, there is an understanding that the work would involve engagement with underrepresented groups.

Initially, some staff perceived me as the 'Access Police', and believed that my role was to enforce DDA (1995) 'compliance' on the organisation. For example, within the first month of the commencement of my part-time role I found out that a new publicity leaflet had been 'signed off' on a day that I was not in work. Members of the Centre's marketing and designer staff had 'plotted' this due to their concern that I would suggest changes to their design to make it more accessible. In the early days of my tenure there was a predominant perception

that I was there mainly to advise on technical issues like the gradients of new ramps in the building works. As the money for the access post came from a grant-funded project, the position was initially situated on the periphery of the organisation.

From this 'peripheral insider' position it was difficult for me to overtly map changes to the working practices of my colleagues. If I had openly been collecting data at key meetings, or regularly interviewed staff about their working practices, it would have compromised my role with the Centre as staff might then have been less open with me about access issues. If the organisation had already been working on access issues for a number of years, and had already started to work with disabled people, I would have been in a very different situation in both my access role and in relation to what was achievable within the research. Therefore, these factors had a large influence on the approach taken within my work and in the study.

### ***Case Study Group: The Nottinghamshire Pioneers Forum***

As outlined by the 2009 Disability Support Team leaflet, the Pioneers 'provides an opportunity for young disabled people to have a voice in different aspects of their lives. This can be by giving and sharing information in youth forums or by representing young people's views through consultation with outside agencies' (DST 2009, 3). As Margaret Clement explained in her interview, the Pioneers were previously involved in producing a sculpture for Rufford Country Park in Nottinghamshire, and had produced access audits for various organisations, including Sherwood Pines, a forest park in Nottinghamshire. With the sculpture project, the artist took the group's ideas and interpreted them without their input,

and unfortunately, at the end of the process the group was not happy with the final sculpture. With regards to the access audits, the group audited the venues and produced reports, but they were not involved with the organisations to implement their recommendations. In both cases, the Pioneers had no control over how their ideas were used by the organisations. In Margaret's interview, she indicated that the emancipatory principles were in alignment with the principles that the youth workers followed when supporting the Pioneers. Common elements in both approaches aimed to support the young people to take control of agendas, to support their access needs and so enable their involvement in projects, to ensure that the Pioneers directly benefited from their involvement, and to challenge the inequalities that the group identified. Consequently, there was a good match between the rationale behind the research and the youth workers' practice.

As described in the introductory chapter, the relationship between the researcher and the Pioneers developed out of a letter of complaint. In our initial meeting, Margaret agreed to raise the idea of working with the Centre and on the research study with the Pioneers, to establish whether they were interested in supporting the Centre to make changes. I then met with the Pioneers on Saturday 15<sup>th</sup> July 2006 to ask for their help. After the Pioneers summer break, the issue was given an agenda spot at their Pioneers Forum meeting on 25<sup>th</sup> November and they decided to form a Holocaust sub-group, as eight out of the 20 Pioneers decided to work on the project. Our first session was planned for Saturday 27<sup>th</sup> January 2007 at their base in Mansfield, and the fieldwork commenced.

Over the 25 sessions, 13 Pioneers attended these sessions. Some of these young people only attended one or two sessions. However, a core group of seven Pioneers attended at least 10 of the sessions. This core group consisted of Kerry Wheatcroft, Sian Davis, Laila Dannourah, Keiron Stobbs, John Georgehan, Lorraine Quincey and Katie Hutchinson, with Michael Pell joining the group later in the process to become an important eighth core member. The young people within the core group had a range of impairments that they disclosed during the sessions or their interviews. These impairments included Cerebral palsy, cognitive impairments due to brain damage, Asperger's syndrome, Dyslexia, epilepsy, Dyspraxia and partial blindness. These conditions represented physical, visual, learning, developmental and cognitive impairments.

During the sessions the Pioneers shared their embodied experiences of living with these impairments, and had valuable knowledge about potential access solutions to improve the Centre. They were, however, not expected to represent the life experience of people beyond their own impairments. For example, none of the Pioneers had a hearing impairment. Alongside the consultation with the Pioneers, the Nottinghamshire Disabled People's Movement also commented on The Journey exhibition's designs as their group had members with different impairments including hearing difficulties. This consultation process was not as in-depth as the Pioneers involvement in the Centre. However, it provided an additional source of support in relation to access improvements.

## Choice of Research Methodologies and Methods

Following Crotty (1998), having established the philosophical basis of the research, the theoretical perspective from which it will be undertaken, and the particularities of the case study, the final elements to consider when planning a research project are the choices of research methodologies and methods.

Figure 21 shows the range of methodologies and methods that were utilised in the study.

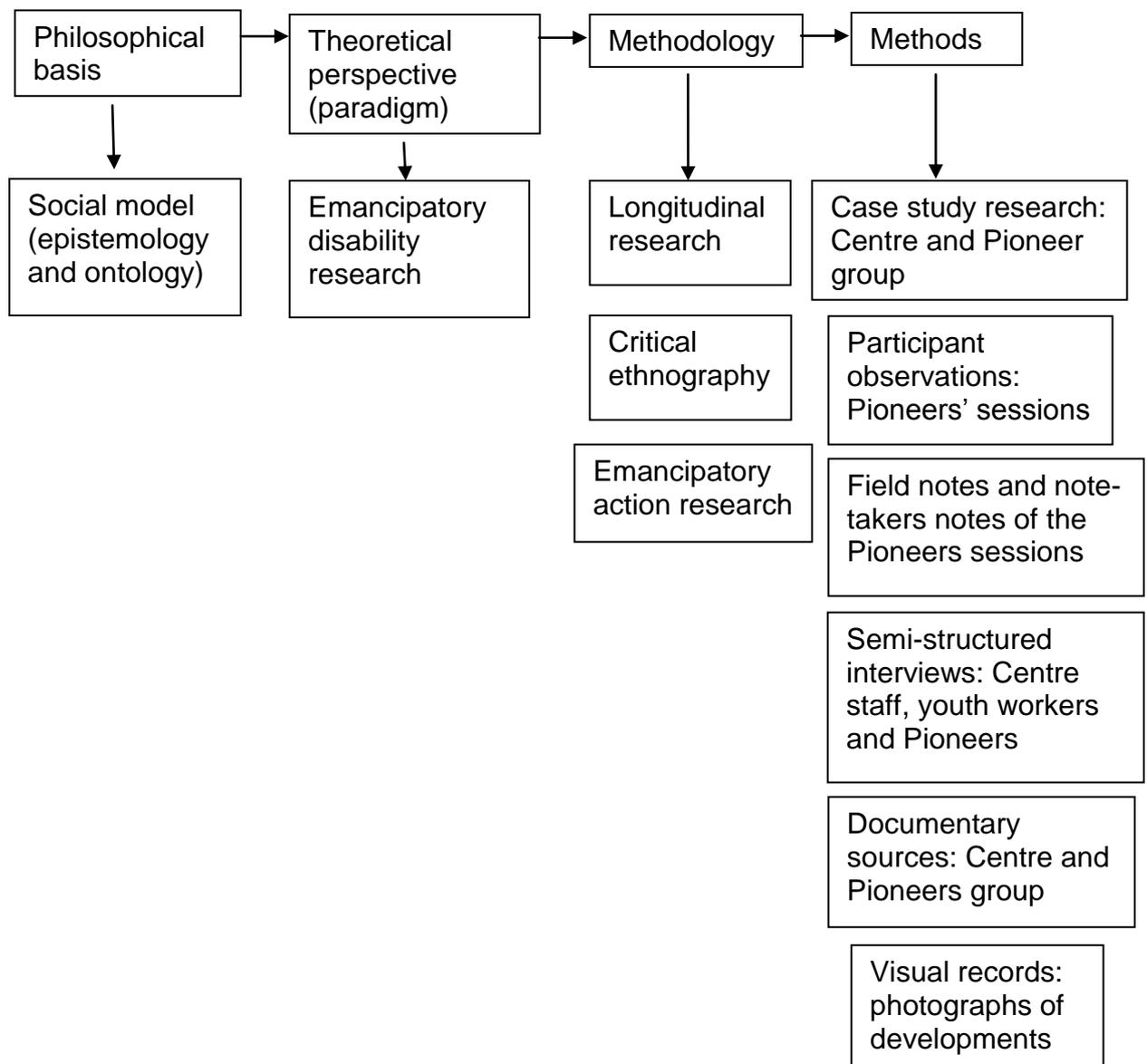


Figure 21: Elements of the research design (after Crotty 1998)

This combination of methodologies was developed as a consequence of following the emancipatory principles, and also as a pragmatic response to how to capture data to reflect the developments within the research project.

## **Methodologies**

When looking at the research methods literature, the methodologies undertaken for this study fall under the categories of longitudinal, ethnographic and action research. The variations of these methodologies that were utilised in the study are described in the next sections.

### ***Longitudinal Research***

This study became longitudinal as the data was gathering over a one year, ten month period. However, the study did not set out to be a longitudinal piece of research, as the time-span was not defined at the outset. Instead, it aimed to track the Pioneers' development to a point where they had achieved a significant proportion of their aims. The time period of the data collection, therefore, needed to be flexible if the research was to be able to respond to developments.

Hammond and Wellington (2013) discuss how longitudinal studies can be exploratory in approach, with McNeill and Chapman (2005) discussing how they are suited to capturing changes over time. However, McNeill and Chapman (2005) state that a drawback to this methodology centres on the recruitment and retention of participants due to the time commitment needed. This point seems valid, as there were some difficulties with this issue during the research. The initial idea of having a 'closed' group which saw the research through from start

to finish had to be modified to allow new Pioneers to join the group, as will be discussed in Chapter 5.

### ***Emancipatory Action Research***

The plan from the outset was for the study to be a piece of action research. The core emancipatory principles of reciprocity, empowerment and gain (Oliver 1992) require the research to benefit disabled people, and demand that disabling barriers in the research process are challenged. An obvious response to these issues was to plan a piece of action research and as Reason and Bradbury discuss (2001, 2), 'a primary purpose of action research is to produce practical knowledge that is useful to people in the everyday conduct of their lives'. Carr and Kemmis (1986), Zuber-Skerritt (1996) and Kemmis (2001) distinguish between three different types of action research:

1. **Technical action research:** aims to improve the effectiveness or efficiency of issues like educational or management practice. The person leading the research is an outside 'expert'.
2. **Practical action research:** aims to reflect on professional practices and by so doing transform them. The researcher and participants work in a cooperative way.
3. **Emancipatory action research:** aims to challenge and change the systems which cause the inequalities that underlie technical or practical issues. The researcher acts more as a facilitator, and the participants collaborate with them.

As can be seen, this present study falls under the heading of emancipatory action research. Kemmis (2001, 92) states that: 'This type of research aims to

intervene in cultural, social or historical processes of everyday life to enact a change' with Zuber-Skerritt (1996) insisting that it should involve researchers being self-reflective and accountable to their participants. It can be seen that these issues are in alignment with the emancipatory principles.

Ledwith (2011) states that a crucial process in emancipatory action research is the creation of critical spaces in which dialogue can co-create new knowledge, which in turn can be used to tackle social injustices. This approach is in alignment with Freire (1972). Ledwith's (2011) approach also focuses on the need for researcher and participants to work as co-participants to dismantle the power relations that are associated with traditional research in favour of a mutual, reciprocal inquiry of equals, which is in-line with the principles involved in emancipatory research. However, an issue that is not strongly highlighted within emancipatory action research is the self-empowerment of marginalised peoples, or how they will directly benefit from their involvement. Consequently, the adoption of emancipatory action research alongside emancipatory disability research adds a new dimension to this methodology.

However, Gray (2004) and Denscombe (1998) raise a note of caution about the limitations of action research. Both authors question whether action research is generalisable to other settings due to the specific nature of the research being undertaken. This issue will be discussed in the concluding chapter of the thesis.

### ***Critical Ethnography***

According to McNeill and Chapman (2005, 89), "Ethnography" literally means writing about the way of life, or culture, of social groups', and that 'the purpose of such research is to describe the culture and lifestyle of the group of people

being studied in a way that is as faithful as possible to the way they see it themselves and to the social contexts in which their behaviour occurs’.

Hammersley and Atkinson (1995) describe a set of features that are central to understanding of ethnographic inquiry:

- The researcher participates in and is immersed in a given setting.
- They take an investigative approach.
- They observe what happens in the setting.
- They pay attention to the language that is used by people in the setting.
- They use a diverse range of methods to gather data.

In terms of this description, the present study would not be categorised as a ‘conventional’ immersive piece of ethnography, as I did not immerse myself in the lives of the Pioneers. In contrast to ‘conventional’ immersive techniques, however, Denscombe (1998) states that the researcher’s role does not need to be totally immersive in approach. DeWitt and DeWitt (2011) draw on Spradley (1980) and Alder and Alder (1987) to define the level of participation that ethnographic researchers can undertake:

- **Passive participation:** when the researcher only observes and does not become involved with the group. They are considered a non-member and external to the group.
- **Moderate participation:** when the researcher has some interactions with the group, but is mainly observing them. They have peripheral membership to the group and are still seen as external to it.
- **Active participation:** when the researcher engages with almost everything that the participants are involved in as a means of trying to

learn about their culture. They are seen as an active member of the group and therefore as an insider.

- **Complete participation:** this occurs when the researcher completely immerses themselves as an insider in the participants' world.

For the purposes of this piece of research it can be seen that I undertook an active participatory approach, as I was immersed in the discussions and activities of the group. However, I was not totally immersed in the participants' world, as the research aimed to focus on a specific issue. Hammond and Wellington (2013) state that a key feature of ethnographic research is the use of participant observations, and in this context I was both a participant in the activities of the group and an observer of developments.

As described by O'Reilly (2009, 9), participation can be conducted from an 'overt' or 'covert' perspective: 'Overt research means openly explaining the research to the participants, its purpose, who it is for, and what will happen to the findings. [...] Covert research is undercover, conducted without the participants' knowledge or without full awareness of the researcher's intentions'.

As it was important that the Pioneers understood that they were involved in a research project, and as the emancipatory principles require accountability to disabled people, this meant that overt research was the only ethical option.

During the research I became an 'insider', as over time the Pioneers came to trust me and see me as part of the Holocaust sub- group. This issue is discussed by McNeill and Chapman (2005) and O'Reilly (2009) in terms of the researcher's status in a group. O'Reilly (2009) identifies the following elements of ethnographic fieldwork:

- Gaining initial access to the group through a gatekeeper and via recruitment of participants (this issue was discussed in the case study section, and Margaret Clement [Senior Youth Worker] was the gatekeeper to the group).
- Establishing the insider role and building a rapport with participants. This issue will be explored in Chapter 5.
- Remaining objective. This issue will be challenged in the next section, on critical ethnography.
- Avoiding 'going native'. The issue of 'going native' is well documented in the literature (Adler and Adler 1987; Shipman 1992; Kleinman and Copp 1993; O'Reilly 2009).

Shipman (1992) defines 'going native' as a process whereby the researcher loses their objectivity and bias, thus interfering with the collation and interpretation of the data. However, emancipatory research calls for researchers to give up their position of objectivity and neutrality (Oliver 1992; Kitchin 2000; Barnes 2003a). This subjective position is in alignment with the sub-field of critical ethnography which according to Thomas (1993, 4), 'is conventional ethnography with a political purpose'.

As outlined by Madison (2012), critical ethnographers need to be very aware of the ways in which they represent the people within their studies, as every representation has consequences, if they take on the voice of authority they may contribute to people's disempowerment. Madison (2012) argues that there is no neutrality in ethnographic research, and goes on to state that critical ethnographers 'contribute to emancipatory knowledge and discourses of social justice' (2012, 6). According to Thomas (1993), 'conventional' ethnography

studies culture for the purposes of describing it and assumes the status quo, whereas critical ethnography focuses more directly on defining and tackling societal issues (O'Reilly 2009). 'Critical ethnographies therefore attempt to expose the hidden agendas, challenge oppressive assumptions [and] describe power relationships' (O'Reilly 2009, 52). According to Thomas (1993, 4), this means that 'critical ethnographers use their work to aid emancipatory goals or to negate the repressive influences that lead to unnecessary social domination of all groups'. This demonstrates that critical ethnography is in alignment with the principles of emancipatory research, as it aims to challenge issues of power, control and authority.

As O'Reilly (2009, 53) points out, critical ethnography relies on the same methods as 'conventional' ethnography to collect a rich data set through 'direct and sustained observation as well as the collection of other forms of data'. In this study, participant observations were supported by semi-structured interviews, documentary sources and photographs. Before moving on to explore the range of research methods deployed in the study, however, it is worth noting the limitations of ethnography. Due to the specific nature of ethnographic studies, some authors (LeCompte 1982; Fine, Morrill, and Surianarain 2009) argue that it can be difficult to generalise from the findings to apply to a wider context. In addition, due to the large data set collected through this study it was difficult to follow the 'conventional' ethnographic approach of focusing on nuances of language and behaviour. Instead, the approach drew on critical ethnography to explore issues of power and control in the data and the emancipatory processes that occurred during the study.

## **Research Methods**

As identified in Figure 21, the research methods that were utilised to gather data in the study were: participant observations, the creation of field notes, the use of semi-structured interviews and the gathering of documentary sources and visual records (photographs). A summary of all the data collected can be seen in Appendix 1, and the approach taken to these research methods is discussed below.

### ***Participant Observations and Field Notes***

During the course of the research 25 sessions with the Pioneers were digitally recorded. The first session commenced on 27th January 2007 and the last session was recorded on 20th October 2008, although I continued to work with the group until December 2008 when I left my post at the Centre<sup>23</sup>. The study therefore covered a one year and ten months period and provided a snapshot of the Centre's work with the Pioneers. The research ended in October 2008, as by then a significant portion of the Pioneers' aims had been implemented with the launch of The Journey exhibition. As discussed by DeWalt and DeWalt (2011, 52), 'the longer the investigator is in the field, the higher the level of trust between community and investigator, and the better quality the information is likely to be'. Hence, there was an advantage that the research developed into a longitudinal study. This also helped to alleviate the 'observer effect' discussed by O'Reilly (2009) and Hammond and Wellington (2013), which states that by observing a situation the observer changes the behaviour of the observed once they become aware that they are under observation. O'Reilly discusses how this

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<sup>23</sup> Another staff member took over the responsibility for working with the Pioneers after I left.

can be minimised by the researcher being accepted by the group over time. As a 'professional' adult, the group gradually accepted me alongside the youth workers, as it became clear that I was there to support their aims.

On average, the group met at the Centre for a two-hour session every three weeks. Of the 25 recorded sessions, 22 focused on the Pioneers creating and implementing their aims, one was a study visit to the Holocaust exhibition at the Imperial War Museum, London and two covered events at the Centre that the Pioneers were involved in. As stated by Hammond and Wellington (2013, 62), the key research method employed in ethnography is participant observation, and as the sessions were digitally recorded, I could concentrate on participating without needing to remember specific conversations to record later on, in note form. The digital recordings therefore ensured that an accurate record of the sessions could be transcribed and important details would not be lost. My field notes could then focus on my thoughts about issues that arose during the sessions.

From Session 17 onwards a note-taker was introduced with the consent of the Pioneers. As I was fully involved in the sessions, it was sometimes difficult for me to stand back and observe the group. This was particularly significant with one member of the group, Kerry, who was selectively mute and did not speak during the sessions. It became obvious that her contributions to the group were not being fully recorded through the transcripts. The group consented to a note taker being present, and the note taker went on to be commissioned to transcribe both the sessions and interview data. As they had met the group and got to know their voices, this approach aided the accuracy of the transcriptions.

Once each transcript was produced I then checked it for accuracy against the audio recording.

On a final note about participant observations, O'Leary (2004) discusses the researcher's positionality. She states that the process of observation is not just simply about watching a group of people and recording what the researcher sees. It is more complex, and the researcher needs to examine the lens through which they are observing people. The researcher's history, biases, interests, experiences and expectations can affect the way that behaviour or events are observed, recorded and interpreted. This issue will be explored further in the section on my positionality as a researcher.

### ***Semi-structured, One-to-one Interviews***

Denscombe (1998) describes three types of interviews: structured, semi-structured and unstructured. I undertook interviews with the Holocaust Centre staff, the Pioneers and the youth workers at the end of the project to allow all parties to reflect on the research process. This was particularly important for the Holocaust Centre staff as I had not been able to track organisational development during the project, due to my dual role as a researcher and member of staff. The semi-structured format allowed me to tailor the questions to the different parties involved, and also deviate from the pre-set lists of questions if I needed to ask follow-up questions to better understand the meaning behind participants' answers (see Appendix 2 for a sample of this approach).

### *Interviews with the Pioneers Group*

Interviews were conducted with six of the Pioneers<sup>24</sup>, three youth workers and a community artist, David Mayne (who had been involved with the Pioneers during the research). These interviews ranged between 30 minutes and nearly three hours in length. The Pioneers' interview questions focused on gathering the following:

- Background information: name, age, how long they had been in the Pioneers.
- Their views on the development of the Holocaust sub-group and the research project.
- Their views on what had changed at the Centre and the Pioneers' influence on these changes.
- Their perceptions of how the research had benefited them and what they had learnt through their involvement.

These questions were reframed for the youth workers to look at the same core questions, but from their professional perspective.

### *Interviews with The Holocaust Centre Staff*

Between September and October 2008 interviews were conducted with all twenty members of staff, with an additional interview conducted with Marina Smith (retired founding member of the Centre). These interviews ranged from 45 minutes to one and a half hours in length. A sample copy of the staff interview

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<sup>24</sup> Of the core group of the Pioneers Sian Davies Kerry Wheatcroft declined to be interviewed. As I was aware that Kerry would not be comfortable with an one-to-one face-to-face, I also discussed sending her questions via email, but she did not want to be involved in this element of the research.

questions is included in Appendix 2. As can be seen, these questions focused on gathering information about: staff members' roles and views about the purpose of the Centre, their views on disability barriers/access issues on-site and the changes they had observed during the fieldwork period. They were asked what they knew of the Pioneers' work and whether they thought it had influenced the staff and site developments. Additionally, they were asked about the disability training they had attended and their work alongside the Pioneers at a disability history event. They were also asked about whether their working practices had changed, and to think about the factors that they considered were supporting or inhibiting changes at the Centre. A similar set of questions was asked of Stephen and James Smith, the Chief Executives, and their questions additionally focused on matters relating to how the Centre was founded, the management of the Centre and their role as leaders. Marina Smith was also interviewed about her reflections on how the Centre was founded. As previously discussed these interviews were then transcribed to aid their analysis.

### ***Documentary Sources and Visual Records***

Strategic documents were gathered from the Centre (Hollins 2005; THC 2005b; 2006; 2007a; 2007b), along with publications that discussed its development (Smith 2002; THC 2005a). These documents provided an interesting institutional perspective on its priorities and working practices. Documentary sources were also gathered from the Pioneers, including the youth workers' planning sheets and minutes that the Pioneers produced at the sessions.

Photographs of the Centre were taken at the start and end of the fieldwork, so that visible changes could be identified. Photographs were also taken to record

significant activities or developments during the research. These visual records supported an analysis of the complexity of the issues surrounding whether the Pioneers had an influence on the Centre.

Overall, the material from both case study elements constituted a large and rich data set to use as a basis for the analysis. The benefit of this was the creation of multiple data sources for comparison and triangulation. The disadvantage was that it created over 250 hours of digital recordings to be transcribed and analysed, posing a challenge for the identification of significant pieces of data. The approach that ultimately enabled this analysis is discussed at the end of this chapter.

## **Ethics and Informed Consent**

### ***Issues Relating to the Pioneers***

As the fieldwork commenced on 27<sup>th</sup> January 2007 before the implementation of the University of Leicester ethics procedure on 1<sup>st</sup> October 2007 (University of Leicester, n.d.), an ethics application was not submitted. However, this did not negate the significant ethical responsibilities that this research entailed in particular, the vulnerable nature of the young disabled people involved, the challenges of achieving informed consent and the emotionally distressing nature of the Holocaust subject matter.

As the Pioneers were classed as vulnerable children or adults (the Pioneers were aged between 15-21 years), informed consent was obtained for the research. However, this was not achieved through the standard procedure of

creating a research information sheet for the participants to read and a consent form for them to sign (University of Leicester, n.d.). Written formats were deemed inappropriate as a method for gaining informed consent due to the Pioneers' learning, cognitive or developmental impairments. Hence, in Session 1 the Pioneers gave verbal consent for their involvement in the research, and in Session 6 this issue was checked to ensure that all of them had understood what they were consenting to. With the one-to-one interviews their verbal consent was again sought. In Session 16 the Pioneers were asked whether they wanted their names to be included in the study, or whether they preferred to remain anonymous. They were unanimously adamant that they wanted their names to be included in the thesis. As the research did not involve a 'closed' group, when new Pioneers joined the project these issues were verbally explained to and agreed with the new members.

A further ethical consideration was that the content of the research at times would be distressing in nature, as the history of the Holocaust can cause deep distress for people who engage with it. Shimoni (1991, xii) describes learning about the Holocaust as a 'particularly sensitive and emotion laden subject'; this was certainly so for this study, as the Pioneers would encounter the history of disability in the Holocaust, when people with impairments similar to theirs were sterilised or killed. This issue was discussed with Margaret Clement in our initial meeting. Her experience was drawn upon to develop an approach to the sessions, at which the Pioneers were encouraged to openly share their opinions, concerns and feelings. This supported them to voice whenever they felt distressed by issues, so that they could receive appropriate emotional support. Thus, careful consideration was taken to ensure that the research was

conducted in an ethical way which was sensitive to the Pioneers' emotional needs.

### ***Issues Relating to the Youth Workers and Centre Staff***

Technically, the youth workers could also have been classified as vulnerable adults as all the members of staff who were involved in the research were disabled people. However, the youth workers were experienced, trained and qualified professionals, and their impairments did not mean that they were inherently vulnerable as people.

To achieve consent from all the youth workers and Centre staff an information sheet was used to explain the research, and all adults signed a consent form. Both youth workers, Stephen and James Smith agreed for their names to be used in the thesis. However, some of the Centre staff wished their names and job titles to be anonymised. Therefore, all other Centre staff have been anonymised within the thesis, and only broad terms are used to describe staff roles.

### **My Positionality as a Researcher**

In their article 'All We Are Saying is Give Disabled Researchers a Chance' Oliver and Barnes (1997) state that despite the emergence of the emancipatory agenda, the opportunities for disabled people to act as researchers have still remained limited. They point out that due to barriers to education and the workplace disabled people do not always receive the support that they need to become researchers. They go on to say that they do not believe that having an

impairment is a prerequisite for undertaking disability research. However, they question the track record of non-disabled people, and state that they would like to see more disabled researchers within the field. Some authors, such as Branfield (1998), go further, and strongly argue against the involvement of non-disabled researchers. Indeed, she calls for positive discrimination to ensure that more research is undertaken by disabled people. However, Barnes (1992a, 121) states:

I am not convinced that it is necessary to have an impairment to produce good qualitative research within the emancipatory model. Analytically, the experience of impairment is not a unitary one. The range of physical, sensory and intellectual abilities within the disabled community is vast. Some people experience a lifetime of disability while others only encounter it later in life. Having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research. [...] The cultural gulf between researchers and researched has as much to do with social indicators like class, education, employment and general life experiences with impairments.

This explores some of the complexities involved in understanding disability issues, and Barnes discusses the importance of the researcher creating a dialogue with disabled people to facilitate their empowerment, as undertaking emancipatory research is not about biology but a commitment from researchers to put their knowledge and skills at disabled people's disposal. In Kitchin's (2000) study, disabled people felt more strongly about the researcher being supportive of disability agendas than the need for the researcher to be disabled. However, his respondents did think that a relationship with a disabled researcher would be more comfortable for disabled participants, as they would understand some of the fundamental issues of living with an impairment. Overall, Kitchin's disabled respondents felt that the ideal model was 'one of inclusivity: an equal-based, democratic, partnership between disabled people

and disabled/non-disabled academics. The model did not preclude non-disabled researchers, but positively welcomed them' (Kitchin 2000, 45). An important consideration is raised by Barnes (1992a) who indicates that it is important that researchers have first-hand experience of working with or supporting disabled people in order to promote an understanding of their lives. This concurs with Kitchin's (2000) respondents, who believed that non-disabled researchers should undergo disability awareness training so that they would have an appropriate frame of reference.

As a non-disabled researcher, my position was therefore contested. However, the majority of the literature supports the involvement of non-disabled people in emancipatory research, as long as they adopt the social model and seek to support the political cause of combating the oppression that disabled people face. The aims of this study were clearly in alignment with these issues. As raised by Barnes (1992a) and Kitchin (2000), I have undergone general disability awareness training, including more specific forms of training related to the needs of the Deaf community, visually impaired people and people with learning impairments. For the past 17 years I have worked on access and inclusion initiatives with disabled people in my museum career.

In terms of other limitations affecting my ability to undertake the research, in my career I have worked mainly with adults rather than young disabled people. However, I was fortunate in that the youth workers were able to support me, so that I could learn from their approach. Throughout my work with the Pioneers I gained new skills to enable me to support them.

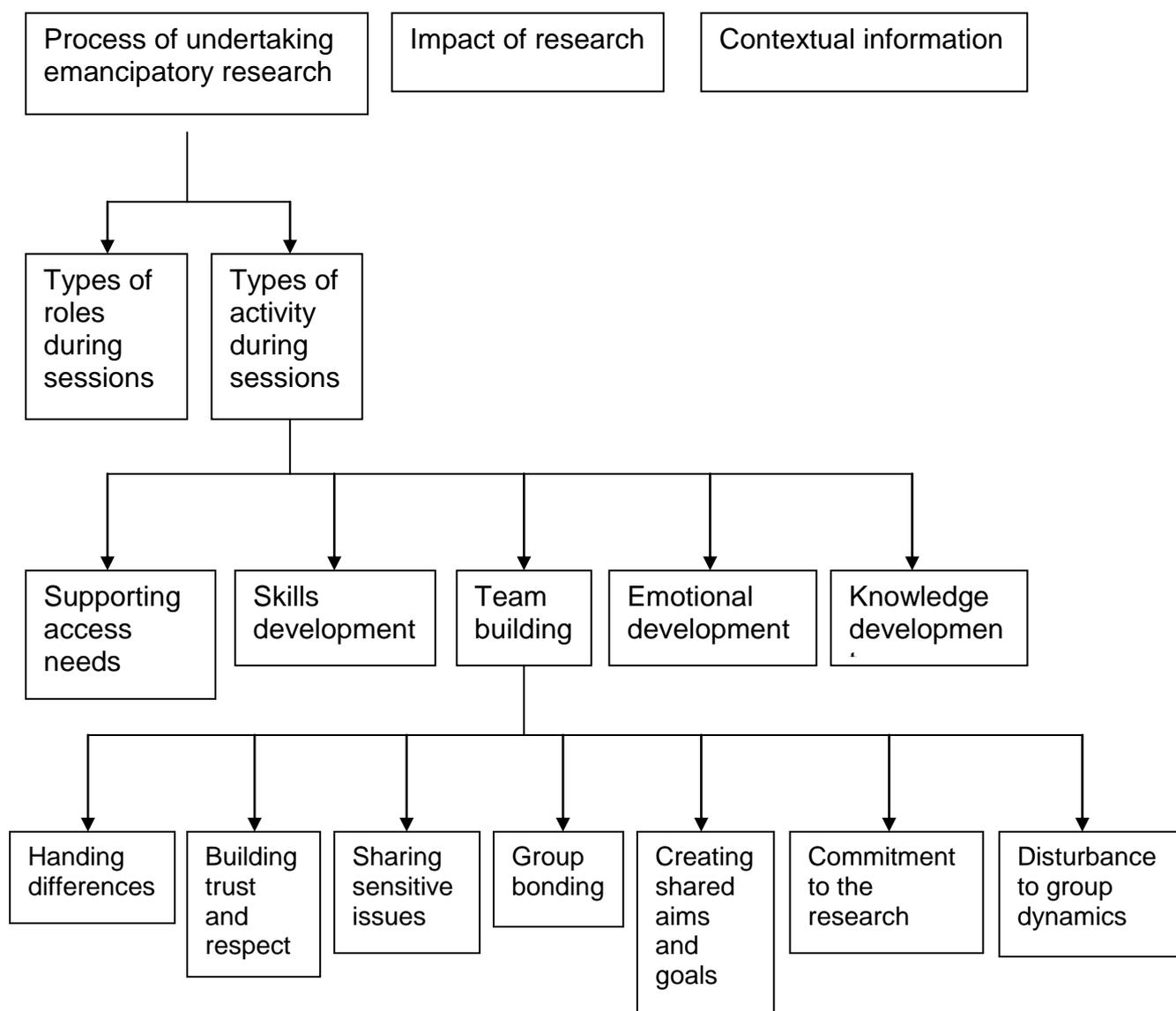
## **Analysis of the Data**

With a large data set it is important to have a clear rationale for how to go about the analysis so that the 'hidden' meaning can emerge. There are various options for how to go about analysing data; however, I had two aims when exploring the collected data. First, I wanted to examine whether issues such as the Pioneers being supported to lead on the research agenda were present in the data.

Therefore, there were certain subjects that I wanted to identify within the data that were linked to the research question and literature. Second, I wanted to be open to issues that arose from exploring the data. When investigating the literature concerning data analysis techniques, the approach that allowed this dual focus was thematic analysis. As stated by Guest, MacQueen and Namey (2012, 11), thematic analysis is 'the most commonly used method of analysis in qualitative research' and according to them it is 'the most useful in capturing the complexities of meaning within a textual data set'. They describe how themes from within the data are developed into a set of 'codes' that help to explore 'real-world problems' (Guest, MacQueen, and Namey 2012, 17). They also state that the main strength of the thematic approach is that it is well suited to large data sets.

To help the themes emerge and to organise the data QSR NVivo Version 8.0, a form of Computer-Aided Qualitative Data Analysis Software (CAQDAS) was utilised. According to Creswell (2003), Richards (2005) and Wickham and Woods (2005), the value of such software is its ability to help researchers to manage and code their data in a way that makes it accessible and easily retrievable. Initially, significant passages on the printed transcripts were highlighted in different coloured pens to start to identify key themes that

emerged from the data. In-line with Basit (2003), Davidson and Jacobs (2008) and Bazeley (2010), NVivo was then utilised to help identify the way that the themes were interconnected to create a hierarchy. In NVivo, this hierarchy is referred to as a 'Node Tree', and this tree enables individual themes to be grouped together. Figure 22 shows an example of the hierarchy of themes (or codes) developed in NVivo.



**Figure 22: An example of part of the Node Tree developed in NVivo**

As seen in Figure 22, the overall approach to analysing the data involved exploring the issues that arose out of the process of undertaking emancipatory research, the impact of the research and contextual information that the participants discussed. This contextual information included issues such as the Pioneers' discussing their impairments and the Holocaust Centre staff discussing what they perceived as the Centre's purpose.

As each of the overall themes had multiple facets the whole Node Tree is not represented in this figure. However, an example of how the themes fitted together into a hierarchy is given. For example, following the overall theme of examining the process of undertaking the research, this theme can be split into issues related to the roles that people undertook in the group and the activities that occurred during the sessions. Following the theme of activities that occurred during the session, it can be seen that this theme can be sub-divided further. Looking at each of these codes they can then be further divided into facets that contributed to each sub-theme. For example, it can be seen that there were a range of issues that contributed to the team building process which occurred in the early stages of the research. Through this hierarchical organisation of codes, a picture was built up that highlighted which issues were the most significant. When viewing Chapter 5 it can be seen that these themes then shaped the analysis.

## **Conclusion**

This chapter has explored the underlying philosophies and principles that shaped the research. It has also explored the implications of disabled people's historical exclusion from the research process, and the subsequent development

of the emancipatory paradigm. These issues underpinned the choices of the research methodologies and the methods used to gather data. The issues surrounding my status as an insider in the Pioneers group, and also amongst the Centre's staff, were examined. The range of data collected and the approach taken to its analysis was also investigated.

Just as the research questions were divided into issues related to the process of undertaking the research and the outcomes of following the emancipatory principles, the next two analytical chapters will mirror this approach. This will enable an analysis of whether the Pioneers were able to take control of the research agenda and influence changes to the Centre.

# **Chapter 5: The Process of Undertaking Emancipatory Disability Research**

## **Introduction**

Focusing on the data that was collected during the study, this chapter explores what happened during the fieldwork. It looks across the 25 recorded sessions with the Pioneers, in conjunction with the interviews that were completed with them and the youth workers at the end of the fieldwork. It analyses the process behind the Pioneers becoming informed decision-makers, how they took control of the research agenda and the decisions they made in relation to their work with the Centre. Chapter 6 will then examine the outcomes of the research for the Pioneers, the youth workers, the Centre's staff and the organisation as a whole. Hence, this chapter aims to deconstruct the process of undertaking emancipatory research. To provide a context for the implementation of the action research the content of the first session will first be described and interpreted, giving a flavour of how the sessions were delivered. If extracts from sessions were the only elements presented, without an overall context some issues such as the absence of Kerry Wheatcroft's voice, who is selectively mute, would not come through in the discussion.

## **Format of the Pioneers Sessions**

Initially, the Pioneers sessions were held at the disability team headquarters in Mansfield. This venue was where the Pioneers group met for their main forum meetings, so the group was on 'home ground' and in a safe and trusted

environment. This was important because at the start of the process the members of the Holocaust sub-group, which was formed from the main Pioneers group, did not necessarily know each other well. Session 1 was delivered on Saturday 27<sup>th</sup> January 2007 (10.00 a.m.-12.00 p.m.).<sup>25</sup> Two hours was the typical length of the sessions, and the content was developed by Pam Ellison, an experienced youth worker. Four youth workers<sup>26</sup> (Margaret Clement, Pam Ellison, Audrey Gardner and Val Marshall) were allocated by Margaret Clement (Senior Youth Worker and Team Manager) to support the project, due to the sensitive nature of the subject matter and the range of access needs of the Pioneers. This was a significant staffing commitment on the part of the youth workers. The youth workers had a particular remit when working with the young people that was different to the type of support they might receive in school/college (where support staff specifically focus on supporting their educational needs) or social workers (who get involved when young disabled people are at risk of abuse). The youth workers focus on supporting the young people with the transition from childhood to adulthood. Boylan and Dalrymple (2009) explain the importance of this transitional period stating that for some young people this transition can be particularly challenging, and that they might therefore need additional support to help them to manage this point in their lives. The adolescent years are a time when young people are making choices about the direction of their lives on leaving school. This involves thinking about future employment options and negotiating issues of autonomy and independence within the family setting, whilst also navigating the complex territory of their evolving self-identity (Spence 2005; Young 2006; Batsleer and Davies 2010).

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<sup>25</sup> A list of all the Pioneers sessions and their dates can be found in Appendix 1.

<sup>26</sup> Four youth workers supported the Pioneers in sessions one to nine. When Val moved jobs he was not replaced by another worker.

For young people with impairments, this transition can be even more complicated, as their impairments – or society’s perceptions about them – can limit opportunities for further education and employment (Young 2006).

The DST youth workers’ approach is to identify personal, educational and developmental issues with the young people and support them to grow. In the context of this project this involved initially leading the Pioneers’ Holocaust subgroup. However, the long term approach of the youth workers was to support and empower the young people to make changes for themselves. They therefore, moved from a leadership role into a facilitation and support role. In this project this process occurred between sessions 5 to 8 as the group began to develop their own aims for the action research, and began to move into the role of informed-decision makers. The process of the Pioneers becoming informed-decision makers will be discussed in more detail later in this chapter.

In Session 1 the youth workers led the content. However, in later sessions the Pioneers were supported to lead on setting the session agendas, and the content revolved around activities to help them implement their own ideas, rather than engage in pre-prepared activities as seen in earlier sessions. Pam began the first session by asking everyone to introduce themselves and where they lived (the Pioneers came from across the north Nottinghamshire area). Importantly, this activity enabled everyone to speak early on in the session and share something about themselves.

Pam introduced the session content and began with an activity called ‘check in’, involving everyone in a discussion about how they felt about their week.

Members of the group were encouraged to discuss both positive and negative

issues. The atmosphere created by the youth workers was both supportive and relaxed. For example, when Val (youth worker) explained his embarrassment about getting lost on a recent journey, there was laughter, but news such as Claire moving into her first flat was treated with sensitivity. The youth workers and I shared our experiences as well as the Pioneers. To build on this practice of sharing feelings, Pam moved on to an activity based around words/emotions written on cards, including 'fed up', 'very upset', 'sorry', 'furious', 'very ill', 'hurt', 'in love', 'embarrassed', 'really happy' and 'unable to cope'. The Pioneers were given time to think about the feeling written on their chosen card before the discussion commenced. This time delay was important, as some of the Pioneers' learning impairments meant that it was not easy for them to express how they felt, and the extra time supported them to cognitively process the information before they spoke.

For Kerry Wheatcroft, this type of activity posed a great challenge. Kerry has Asperger's Syndrome and found it difficult to talk in group situations. Kerry chose not to join in with the activity, and throughout the early part of the session she sat at the table with her back to the group and her arms folded. She had a troubled expression on her face, but no-one commented on this, nor did anyone draw attention to Kerry or try to coerce her to join in. As Kerry was an established member of the main Pioneers group there seemed to be an understanding that she would join in if she felt able. At times she left the room when the social situation became too difficult for her.

The youth workers facilitated the discussion, supporting the Pioneers to take turns sharing their feelings, and this in-depth activity lasted 22 minutes. The creation of an encouraging atmosphere allowed the Pioneers to see that when

they shared something difficult no-one laughed at them or dismissed their feelings. This was important, as many of the Pioneers had experienced bullying and found it difficult to have a voice within their families and peer groups (an issue identified in Margaret's interview). After Pam thanked everyone for their involvement, Margaret took over the facilitation role, signposting the remaining content for the session.

At this point she raised the issue that the Pioneers had options about what they wanted to work on with the Centre. Lorraine mentioned that she had been to Auschwitz, and there was a general discussion about what Lorraine, Laila and the youth workers knew about Holocaust issues. Laila had previously studied the Holocaust at secondary school, and so had some background knowledge. This led to Margaret mentioning a recent article by Shakespeare<sup>27</sup> (2007) in the 'Disability Now' magazine, in which he discussed the disability history of the Holocaust. This prompted Laila to raise the case of 'Ashley X' from the USA, which had been in the media. Controversial ethical issues were raised by this case, as the child's parents went to court to seek permission for surgery and hormone treatment that would prevent her from entering puberty, making her long-term care easier for her parents to manage. Laila voiced strong opinions about the rights of young disabled people, and this discussion introduced a link between contemporary disabled people's rights, and how prejudice led to disabled people's persecution and death during the Holocaust. This in turn began to create a connection between how work with the Centre might have relevance for the young people's lives. A discussion about the Pioneers' potential involvement in the research project followed, and I discussed the idea

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<sup>27</sup> Tom Shakespeare is a prominent disability activist and academic.

of the Pioneers getting involved in gathering data. Laila and Keiron showed an interest in this option.

The group then broke for a 20 minute tea break, allowing a mental break as everyone had been concentrating for nearly an hour. The group chatted informally whilst refreshments were served. The break also provided an opportunity for the youth workers to talk on a one-to-one basis with any Pioneers who looked as though they had been affected by the content. For example, Margaret checked whether Kerry was coping with the social group situation. During the tea break, Laila and Keiron asked to look at the digital recording equipment, and Kerry asked to use the digital camera. She moved around the building taking pictures of features that she thought were important. This was significant for Kerry, as it meant that she could engage with the project on her own terms. In future sessions she took on the role of photographer for the group as she felt more in control if she was behind the camera. After the tea break, Kerry did not return to the group as she did not feel comfortable. However, she stayed close by on-site. The staff did not pressure her to return, and did not make an issue out of her absence.

In the second half of the session, Pam facilitated an activity designed to get the Pioneers to think about people who had supported them through difficult situations. This was followed by an exercise intended to elicit an understanding of what the Pioneers knew about the Holocaust and the Centre, to begin to gauge what they wanted to gain from the project. This section of the session was predominantly led by Margaret and Audrey, as the Pioneers did not know how to respond to the questions. Pam suggested that the next step could be a visit to the Centre, which the group was enthusiastic about. Rather than arrange

the visit, the youth workers encouraged the Pioneers to think about how to organise it, and supported them to put their ideas into action. There was a long discussion (over 30 minutes) about finding a suitable date and working out the logistics of how to get to the Centre, which is in the middle of rural Nottinghamshire with poor transport links. Kerry rejoined the group towards the end of the session, and even though she did not speak she was able to indicate that one of the dates was not possible for her, and a suitable date was chosen for the whole group.

After a practical activity in which the group described the qualities of their ideal person to support them with the Holocaust project, the session ended with the group discussing what they had got out of the session. Kerry managed to stay throughout the last part of the session and went for lunch with the group, which was an achievement.

The format of this session highlights several issues. Initially, the youth workers led the session content and the Pioneers' views were not at the forefront of the discussion around options. However, this pattern changed over the first five sessions as the group got to know the Centre and started to understand possibilities. It was also noticeable that I was not at the forefront of discussions, although I did join in with the activities. In the early stages of the project I needed to understand the ways that the youth workers supported the Pioneers and the ways that the sessions were structured and facilitated. I was quite conscious of not imposing my aims, as I wanted to give them space to develop their own.

When analysing the data in relation to the implementation of the emancipatory principles a whole series of issues were highlighted, which can be grouped under four broad headings: team building; the Pioneers achieving informed decision-making; the development of advocacy skills and the Pioneers taking control of the research agenda. After analysis of these issues, at the end of the chapter I will revisit the emancipatory principles that were outlined in Chapter 4 to analyse whether the research was able to follow them.

Following a thematic analysis of the data, the themes that emerged were a mixture of issues highlighted from the research questions and the literature, and unanticipated issues that arose during the fieldwork. For example, issues like team building and the steps involved in supporting young people to become decision-makers were not outlined in the disability literature. These new themes involved an exploration of literature from the fields of management studies (in relation to the development of the group) and also youth work studies to support its analysis.

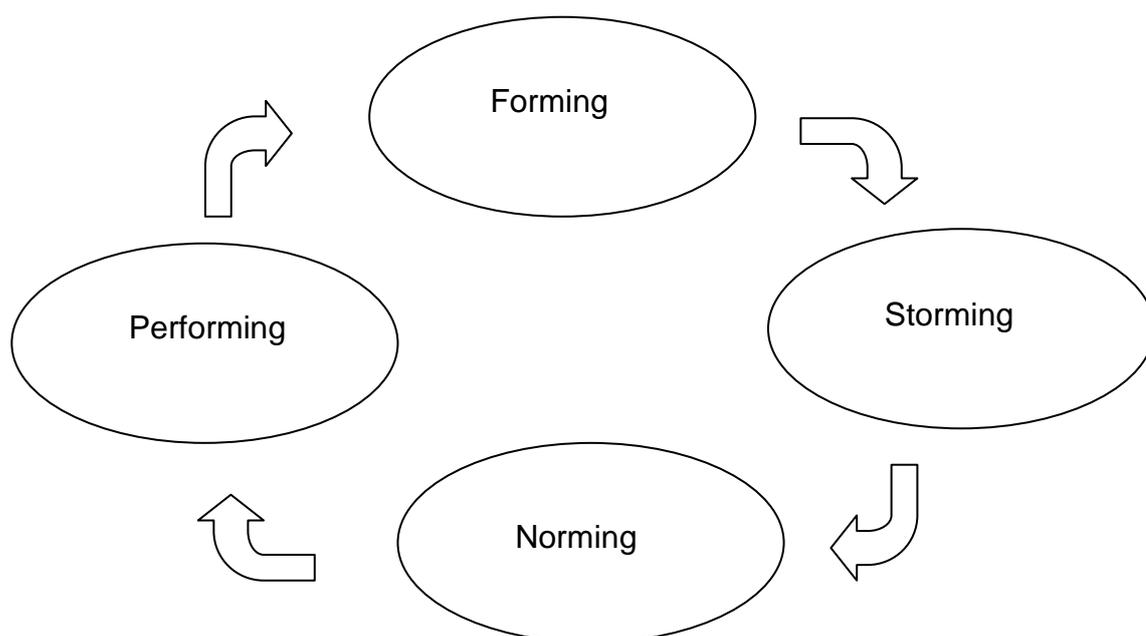
## **Team Building**

From the analysis of the data, it is clear that a process of team building occurred in the first eight sessions. A number of factors were important to the group, with strong bond forming between members to enabling them to work together for a long period of time. These factors involved the group building trust and respect amongst its members and with myself (they already had a relationship with the youth workers). It also entailed them opening up and sharing their feelings, enabling them to discuss difficult issues. This was particularly important when engaging with subject matter such as the Holocaust. The group members also

found a shared sense of purpose once they had developed a set of aims for the action research.

### ***Group Development***

Tuckman (1965) and Tuckman and Jensen (1977) provide a useful model for the dynamic of how groups change over time (see Figure 23). They describe four stages of development: forming, storming, norming and performing with a fifth stage, adjourning that occurs when groups disband. The first two will be discussed in the next section, with the norming and performing stages being examined in a more relevant section later in the chapter.



**Figure 23: Tuckman's (1965) stages of group development**

Tuckman (1965) maintains that groups need to progress through these five phases, in order to face challenges and learn to work together. From the data, it is clear that the group was in the forming phase during sessions 1 to 8, which

coincided with the group bonding and members becoming familiar with one another. During this stage the group began to create shared aims (as will be discussed in the next section).

Although there were other sessions where conflicts arose in the group, in the early stages of the group's development the main sessions when storming occurred were sessions 4 and 5. Between sessions 1 to 4 the numbers attending the group dwindled from eight to two Pioneers. At this point it looked as if their interest was waning, and Margaret went back to the main Pioneers meeting to ask the Holocaust sub-group members whether they were still interested in the project. Several issues came to light. The sessions had been scheduled to begin at 10.00 a.m., which was unpopular with the Pioneers as some of them did not want to get up early on a Saturday morning. As the main Pioneers sessions were also held on Saturday mornings, the young people explained that this left them with little free time at the weekends. The Pioneers were asked whether they wanted to continue with the project, and they were enthusiastic to continue. The decision was made to alter the schedule to 7.30 p.m. – 9.30 p.m. on Monday evenings, which was deemed to be more suitable.

According to Forsyth (2010), who cites Tuckman (1965), in the forming stage members of groups do not often share their true feelings about issues and, therefore, a storming phase is important as it 'gets problems out into the open'; problems which might jeopardise the group if they are not addressed. This was certainly the case with the Pioneers. The group did not share their real feelings about the sessions until the project had almost reached a crisis point in Session 4. The group also indicated there had been a lot of discussion during the session, but not much action. In previous projects they were used to auditing

organisations, producing a report and then moving on so that actions and outcomes happened very quickly. The process of preparing them to work on a longer term project, where they made decisions about what they wanted to achieve and followed them through, was outside their normal mode of operation. This sense of inaction had begun to frustrate the Pioneers. A tension arose between the process designed to enable them to create aims and become informed decision-makers and the time this was taking. There was a risk that the project would end due to this perceived initial inertia. As such, it was important that the Pioneers were listened to and changes were made. Overall, it took ten sessions (eight months) to create a stable group centring on the core group of Pioneers. It can be argued that, following Black's (2006) assertions about the peripheral and short-term project-based work that many museums engage in with respect to marginalised communities many projects would not commit to this length of time to support a group to form fully, especially within the context of the group having no set aims at the start of the project. When the agenda for project work rests with the museum there is an anticipation that the community will fit in with the timescales of the museum and its needs (Lagerkvist 2006; Lynch and Alberti 2010; Lynch 2011b). However, with this piece of action research there was no pre-set agenda or timeline to follow. As it was a 'test-site' case study (Denscombe 1998) which aimed to explore an experimental methodology, I was willing to follow the group in whichever direction it moved.

One final note about the recruitment of members to the group, the idea was that the sub-group working on the Holocaust project would be a 'closed' group, which meant that the initial members would see the project through to completion. The thinking behind this was, given the sensitive nature of the Holocaust, it would be

better for a 'closed' group to see all of the stages through. However, due to the faltering numbers, this turned out to be unrealistic, and an 'open' group was developed that allowed for the recruitment of additional Pioneers. Steps were taken to induct the new Pioneers into the group so that they could understand how it worked and join in with its aims.

### ***Bonding as a Group***

Humans are social beings, and the successful development of a group depends on people getting along, cooperating and building trust with one another (Silverman 2010). As outlined in Margaret's interview, an initial important factor in the group's formation was the creation of a safe space. As the St Ethelburga's Centre for Reconciliation and Peace<sup>28</sup> (2009, 1) outlines in its guidelines on 'Creating Safe Space for Dialogue and Group Work':

Safe space is a fundamental requirement for authentic and meaningful dialogue in diverse groups. This is particularly important when the focus is on conflict and reconciliation, or the theme is a sensitive one. [...] The perceived safety of an environment will have a direct impact on the ease with which relationships are formed and their sustainability.

Initially, as noted above, we met at the Pioneers' base in Mansfield. From Session 5 onwards the group met at the Centre, and so there was a process of getting to know this space. In Margaret's interview she talked about the Pioneers starting to feel familiar with and comfortable at the Centre. The sessions also involved a process of building trust, so the Pioneers could see that when they voiced concerns/opinions they were listened to, and that the Centre acted on them. It involved the Pioneers getting to know and trust me, as Audrey revealed:

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<sup>28</sup> St Ethelburga's Centre for Reconciliation and Peace is in the city of London, and was originally a church. After it was blown up by an IRA bomb in 1983 it was transformed into a centre for reconciliation and peace.

There was a process of getting to know you [as] they thought, well, why is she so quiet when she wants us to do something, she's not directly asking us to do something. But you was doing it [...] in a way where you was trying to empower the young people. [...] But they didn't understand you, they don't understand body language. They thought you were quiet, you didn't know what you wanted.[...] once they'd learnt that [...] you wasn't forcing your agenda on them, you was supporting them to make their own agenda then they realised you weren't slow [...] and you weren't just doing the job because somebody told you to do it.

It was interesting for me to hear about the Pioneers' initial reticence about working with me. My approach had been to join in with the discussions and slowly support the Pioneers to create their own agenda. This clearly caused some level of unease amongst the group, however, as I had not acted in a role of authority. As Margaret explained the youth workers were also initially wary of my commitment and unsure whether I had an unspoken agenda behind the partnership working:

You've got a role but what is she really thinking about? What's her agenda? [...] Obviously our methodology might not have been yours, and [...] the fact that you've been able to sit and go with the flow has been really good, because then you're not afraid how long is it going to take? [...] You've been able to just really go with the process, and to me that's really good to have somebody around who's able to do that because that doesn't often happen [and] the conversations we had about your methodology. [...] About your research and our methodology which are quite interlinked in some ways.

Margaret's views show how I gained the youth workers' trust and her comments reinforced the benefits of working in a long-term way with the Pioneers. They also reinforced the importance of the youth workers' methodology being in alignment with the emancipatory approach.

An important issue raised by Margaret in relation to the development of trust was for the Pioneers to know that when they voiced their opinion they were

listened to and taken seriously. During the first access audit the group raised their unease about criticising the Holocaust exhibition.

Val: I don't like this job you know, just going round criticising everything.

Heather: I don't get offended, you're all right. No, because the first time I came around I spotted very similar things.

Laila: It's just that it seems very rude of us.

Heather: No, no, you're doing the right thing. I'd prefer you to say exactly what you think. You won't offend me in any way 'cause I know that there are things wrong with it. I've looked at it and thought similar things, so it's nice to hear what you think.

After this conversation the group seemed more at ease about saying what they thought. The Pioneers' encouragement to voice their opinions and sense that they were being listened to started a process of trust being built between the group and I. Later on in the project they began to see the outcomes of the opinions that they had voiced. For example, in Session 9 a member of the Centre's design team created three different designs that could be installed behind the new reception desk. This staff member asked the Pioneers to look at them to decide which was the most accessible, as they were willing to redesign them in response to their feedback. The group chose the image shown in Figure 24, as they felt that the atmosphere in the photograph conveyed the gravity of the Holocaust and visually represented it well. This was important in particular for the Pioneers who had learning impairments, as some of them found reading difficult. Soon afterwards, in Session 11, they were able to see the image installed in the newly refurbished and accessible reception space (see Figure 25). As discussed by Batsleer and Davis (2010), the process of building trust

and respect between youth workers and young people is an important part of youth work.

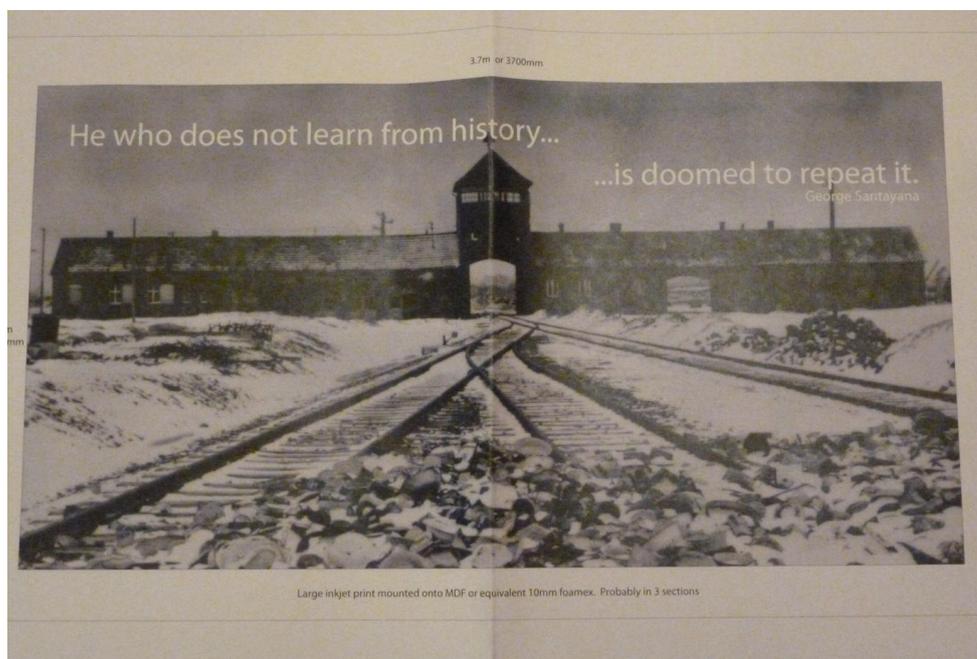


Figure 24: Designer's draft reception image printed out for the Pioneers to view



Figure 25: New reception space, with the Pioneers' chosen image installed

### ***Emotional Development: Sharing Feelings and Difficult Issues***

As discussed above, in the early sessions an important element was for the Pioneers to feel comfortable and able to openly share their feelings with the group. This was in preparation for the more difficult discussions about the Holocaust to come. An excerpt from Session 1 shows Keiron sharing his feelings in relation to attending a funeral on the previous day:

Pam: Keiron what word was yours?

Keiron: Unable to cope

Pam: Unable to cope. [...] Have you ever felt like that Keiron?

Keiron: Yes, yesterday I was unable to cope because of people crying in front of me.

Pam: At the funeral?

Keiron: Yep, so I decided not to cry in front of them.

Pam: You tried not to cry as well. Well, that's another thing, what you said about putting a strong face on things.

Margaret: And it is society's assumption that men shouldn't cry, and that's a hell of a pressure when you think about it, isn't it? When we talk about what we think it's acceptable for women to cry but for men it's not, because society says so. Doesn't matter what you're feeling like, but people assume all those things again.

Val: I just wondered how it felt Keiron?

Keiron: Under pressure.

Val: Under pressure because you've got people crying around you and you want to cry yourself and you're holding it in. Where did all that go?

Keiron: I do it in bed.

Val: You cried alone.

Keiron: Yeah.

Val: Is that because of what people will think about you, or...?

Keiron: Yeah.

Val: Do you not think that sometimes it's nice to be human and to show people who you really are? 'Cos I know I do, I cry.

As Val was a male youth worker he was able to show Keiron that it can be acceptable for men to cry. The group listened to and discussed Keiron's feelings in an open and non-judgemental way.

The Holocaust as a central focus for a project was bound at some point to cause distress to participants. Shimoni (1991, xii) states that learning about the Holocaust is a 'particularly sensitive and emotion laden subject', and Liss (1998, 3) states it is 'a subject of vast enormity and horror which sometimes defies explanation and understanding'. In his interview, John explained how shocked he was when he initially joined the project and began to find out about the Holocaust:

The museum it was very, very emotional. It was very uplifting and it really knocked me back. [...] 'cause I didn't know this was happening [...] to young people.[...] in the Holocaust until I came to The Holocaust [Centre] and then did some research on it. Went back home and then next morning I went to library and did a load of research on it. [...] It did shock me, very, very much. [...] and you look what happened in the Holocaust it's just frightening to see [...] what happened in the Holocaust [to] the Jews and disabled people. It's still happening in the world, like people being mistreated and all that on the news.

Heather: So did you know before that the Holocaust had affected disabled people, had you heard of that before?

John: No, I only got to know about the disabled people by Margaret telling me about it. And then you showing us that picture with all the things stacked up...

Heather: All the equipment at Auschwitz?

John: Yeah.

In Session16 I explained my experience of visiting Auschwitz with the Centre staff, and showed the Pioneers photographs that I had taken (see Figure 26).



**Figure 26: Display of disability equipment at Auschwitz**

In particular, this image of a pile of equipment that had been taken from disabled people before they were led into the gas chambers greatly affected the group. Laila commented that some of the callipers in the pile were very similar to ones that she had worn as a child, thereby making a direct connection with the

impairments of Holocaust victims and those that the Pioneers lived with, and acknowledging that they would have been killed if they had lived 60 years ago in Germany. As can be seen in the conversation above, John also made a direct connection between people's treatment during the Holocaust and the persecution of people today. Therefore, it was particularly important to develop an environment where open and supportive communication could occur.

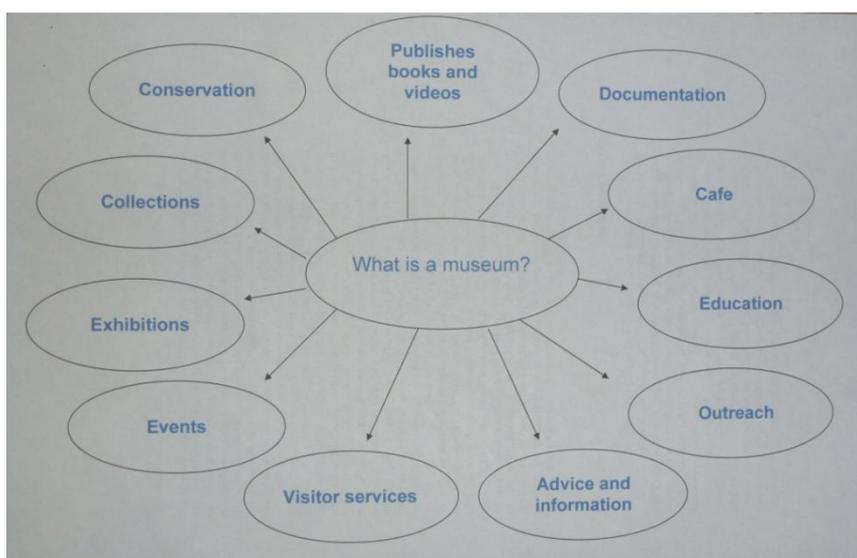
The development of a strong bond between members in the group was important, particularly as some of the Pioneers found it challenging to work in group situations as they found it difficult to read certain signals like body language (an issue raised by Audrey in her interview). In Lorraine's interview she indicated that working as part of a team had been the most important learning experience of the project.

The youth work literature highlights the emotional development of young people as an important issue for youth workers to support. For example, Batsleer (2008) discusses a series of fundamental issues which underpin the development of complex conversations with young people. These include the importance of creating a respectful and non-judgemental space, developing an atmosphere where issues can be discussed openly; she also stresses the importance of building trust with and between young people. Thompson (2005) reinforces the importance of supporting young people to identify and feel comfortable with the complex array of feelings that they might encounter in themselves and others. Silverman (2010) also places an emphasis on 'respectful interactions' and the cohesion of groups in her analysis of museums' engagement with communities. These authors' work justifies the active focus placed on this issue in the early stages of the project.

### ***Developing Shared Aims and Achieving Informed Decision-making***

The final issue that emerged from the data as being important for the cohesion of the group occurred when the Pioneers started to work together to develop shared aims for the action research. A feature during sessions 1 to 3 was the youth workers or I offering suggestions to the Pioneers about potential ideas that they might choose to work on. The aim of presenting them with options was not to make decisions for them, but to open up potential avenues. However, initially the group did not engage well with these conversations, and it could be argued that they did not really understand what was being asked of them. A feature of the early sessions was to familiarise them with the issues that they needed to understand so that they could create their own aims.

In Session 2 I presented the group with a hand-out (see Figure 27) which outlined the range of activities that the Centre was involved in, and this was a starting point to discuss the range of work areas/activities in which they could get involved.



**Figure 27: Photograph of the hand-out from Session 2**

Hence, if they were interested in marketing, we could have focused more centrally on ways to improve approaches to accessible marketing. I was open to the group choosing whatever direction they wanted for the research. A turning point in the group's development came in Session 5, when the group started to develop their own aims for the research for the first time.

In Session 5 the group went to look at the memorial gardens. During the tour we looked at the meaning behind a sculpture entitled 'The Abandoned' by Naomi Blake (see Figure 28). Blake is a child survivor of Auschwitz, and the sculpture is dedicated to the memory of the ten grandchildren within her family who were killed at Auschwitz.



**Figure 28: 'The Abandoned' by Naomi Blake**

During the discussion, Laila noticed that there were no sculptures in the garden dedicated to the disability history of the Holocaust:

Laila: Me and Kerry thought it looked more like a woman than a man. Didn't we? It's strange there's no hands. Are there any sculptures in the garden about the disabled people who were killed?

Heather: No. All the sculptures are about the Jewish people who were killed in the Holocaust.

Audrey: Oh, I didn't realise that. Really?

Heather: Yes all of them are about Jewish people.

Lorraine: There should be some about disabled people. What about disabled people who were killed?

Audrey: There wasn't really anything in the exhibition downstairs. Is there anything that really discusses the disability history?

Heather: No, not really.

Laila: We should do that, then. Oh that would be good. Could we do a sculpture?

Margaret: There's no reason why not. Kerry, I can see you nodding.

Lorraine: We could do a sculpture or summat.

Keiron: I like that. We could do a sculpture. Sculpture of disabled people.

Val: Ok. Well we could think about how to make that happen.

Laila: I like that idea. It means that we can show that disabled people were killed in the Holocaust too.

Heather: Well, I could help you to get permission from the managers to have one in the garden. We can put together some ideas and talk to them. We can think about where it could go.

Margaret: I think that's something we can discuss.

This conversation was a real turning point for the group. It seemed to energise them and make them feel that something could happen as a consequence of their ideas. This conversation was a culmination of five months' work for the Pioneers to get to know the content and purpose of the Centre. It also showed them that when the group suggested an idea the youth workers and I supported them to think about how to put it into action. This idea became one of their key aims, and the initiation of shared aims seemed to move the group into what Tuckman (1965) and Tuckman and Jenkin's (1977) term the 'norming' stage, as the group started to develop a common purpose.

By Session 8 it was clear that the group had genuinely made decisions about the focus of their work and started to implement their plans. This shift towards the implementation of their ideas saw the group moving into what Tuckman (1965) and Tuckman and Jenkin's (1977) call the 'performing' stage. It took six months to support the Pioneers to reach this stage of informed decision-making, and for them to properly take over the lead of the agenda. By this point the group had bonded as a unit, and the development work had laid the foundation for them to work together for the duration of the project.

### **Taking Control of the Research Agenda**

In sessions 5 through to 8 the Pioneers started to make great steps forward in terms of developing their own ideas. After the conversation that occurred about the sculptures, they began to think about the wider range of issues that they wanted to focus on in the action research.

Margaret: So what do we think, then?

Laila: Well, I think a sculpture's a good idea. People who come to the Centre will know that disabled people died in the Holocaust, as they wouldn't know that now, what with downstairs.

Margaret: What do the rest of you think? Let's look at our options. So what have we talked about?

Lorraine: We looked at the exhibition and access. Lots of things... need changing.

Keiron: Yeah, 'specially the stair lift.

Audrey: Yes, you've access audited and we have a list and pictures of what needs changing. What else did we discuss last week?

Laila: Heather brought the plans for the new exhibition. Did you say we could be involved at different stages?

Heather: Yes, there are lots of phases to the designing of an exhibition and you could give advice all the way along. [...] The builders have just been altering the shape of the rooms at the moment and building the lift shaft. [...]

Audrey: We also discussed last week the young people getting involved in the research. They had a practice using all the research equipment, and we talked about them interviewing the staff.

Keiron: I'm not so interested in interviews.

Laila: Yeah. I know we're supposed to be writing in our blue books, but I keep forgetting. Do we have to record things?

Audrey: No, not if you don't want to, but it might be good to see how you've progressed on the project.

Laila: Can't we just meet some of the staff and talk to them, rather than interview them? I think I'd get quite nervous.

Heather: We can practice loads in advance and I can give you some help so you're not nervous. You know we did the practice session with the research equipment. We can do much more of that so you're confident using it.

Laila: I'm not that interested in that. I don't want to be funny, but it's just not my thing. Also, I'm not interested in recording our progress. I'd rather do things.

Keiron: Me too. I like the sculpture.

Margaret: Any other ideas? [...] What do we really want to achieve by working with The Holocaust Centre?

Laila: Well, when we've worked on other projects we've audited them. I'm not being funny but not much of this place is accessible.

Audrey: Yes, you identified lots of issues in the exhibition downstairs.

Margaret: And even getting in is not that easy [laughs]. So what do you want to do?

Laila: I think it needs to be more accessible. We need to talk to the staff about changing things. We need to tell them what we've seen.

Margaret: So you'd like to help the staff at the Centre to improve access. As that's what we do in't it? Rather than tell people a long list of what's wrong, we talk about how to change things. Is everybody in agreement?

Keiron, Lorraine and Laila: Yes.

Margaret: Can I see a nod from Kerry? OK.

Laila: I think the new exhibition's important. We can make sure they don't make the same mistakes again.

Margaret: So you could also work on making sure the new exhibition is accessible.

During this conversation the group decided that they wanted to improve access in the existing exhibition, ensure that the designs for the new exhibition were accessible, create a sculpture about the disability history of the Holocaust and talk to staff about access issues. They also decided that they did not want to gather data for the research. Later in the process they also decided that they were not interested in the analysis of the data or its dissemination.

The conversation about potential decisions was discussed further in sessions 6 to 8 as two new Pioneers, Katie and Sian, joined the group. In Session 8, Kerry brought in a summary of the ideas that the Pioneers had discussed to share with the group (see Figure 29).

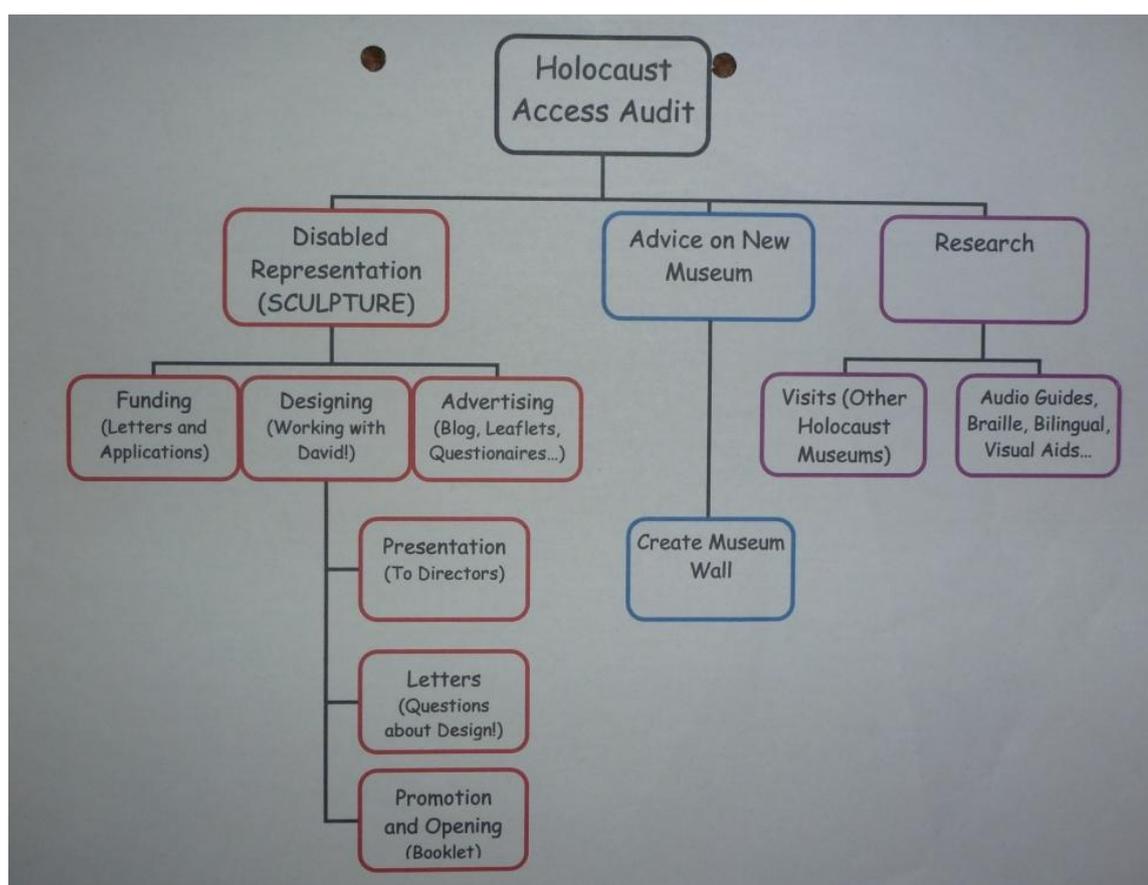


Figure 29: Photograph of Kerry's visual summary

This is noteworthy for two reasons. First, it showed how engaged Kerry had been in the conversations even though she did not contribute in a verbal way. Summarising the ideas was her way of processing these conversations and communicating them back to the group. As Kerry has Asperger's Syndrome it is difficult for her to comment 'in the moment', therefore, having time to reflect and process the information was important to her. Second, this visual summary was supportive for other group members as it provided a clear focus for a discussion on the way forward.

The decisions that the Pioneers made were:

1. To create a sculpture representing the disability history of the Holocaust. The elements that were identified within this included working on the design of the sculpture, looking for funding to implement it and also advertising the group's plans.
2. To advise on access issues within the new exhibition and the wider site refurbishment.
3. To undertake research into the Holocaust and museum access issues. The group decided that they wanted to visit another Holocaust museum and investigate how to create accessible interpretation.

From this point forward there was a shift in the session content as the youth workers and I supported the Pioneers to work on these ideas and implement them. Using Simon's (2010) definitions of participation, the Pioneers' involvement in the development of the new exhibition can be seen as 'collaborative'. According to Simon's definition: 'visitors are invited to serve as active partners in the creation of institutional projects that are originated and ultimately controlled by the institution' (2010, 187). Under Simon's definitions this project was collaborative and 'consultative' in nature as the Pioneers acted as experts and community representatives to provide advice and guidance to

staff during the development of the exhibition. However, they were not in control of how the exhibition plans were implemented.

*The Journey* exhibition had four primary stakeholders: primary school teachers and pupils, Holocaust survivors and disabled people. Consultation occurred with all four stakeholder groups throughout the exhibition's planning and development. Yet, although the Pioneers had direct input into the development of the exhibition, it was not realistic to place the Pioneers into a decision-making role within the exhibition's development, as the choices involved in the interpretive approach necessitated the creation of a balance between all the stakeholders' interests and needs. For example, as the main narrative did not relate to the disability history of the Holocaust, it was more appropriate to consult with survivors over how their testimonies would be represented. In reality, the Centre was in control of whether it accepted the Pioneers' advice. Therefore, following the discussion in Chapter 3 in relation to co-production, the Pioneers' involvement in the exhibition did not co-create new content (as discussed by Govier (2009)) and the process of the Pioneers' involvement was not co-productive (as discussed by Lynch and Alberti (2010) and Lynch (2011a)) as the Pioneers did not co-create and implement the aims for the exhibition.

Following Arnstein's (1969) Ladder of Participation it can be argued that the Pioneers were involved at the partnership level as, although they were involved as partners who were seen to have valuable expertise, they were not involved in power-sharing with the Centre, which meant that they did not reach the higher levels on the ladder of delegated power or citizen control. Lynch (2011a) contends that although museums may aim to share power, they often fall short as staff are unwilling to let go of their control and authority and truly share

power. In this context, the Centre did not intend to share power with the Pioneers. However, it did see them as a valuable group with which to consult. This is demonstrated by Stephen Smith's interview:

I think the benefit has been, first of all, having a reference group that really understands the issues. [...] Being open to their suggestions and seeing their suggestions and ideas as being constructive [...] and acting on them was important. And I think it's also really important to relate the organisation more closely to the community. And if it can't be accessed and referenced by the people that live within its locale then it isn't doing its job. So it also helps us to know we are able to speak properly to our own community.

This excerpt shows how the Centre was open to listening to the group and acting on their advice. Working with an external group in this way was a new approach for the organisation. Additionally, it was willing to support the Pioneers to create a sculpture for the gardens and, using Simon's (2010) framework for considering participation, this aspect is classed as a hosted project, as these are activities where 'the institution turns over a portion of its facilities and/or resources to present programs developed and implemented by public groups or casual visitors' (Simon 2010, 187). In Session 12 the Pioneers met Stephen Smith and presented their ideas. He was supportive and did not impose an agenda on their plans. He discussed where the sculpture might be located, and wanted the group to show him their design so that the senior management could see what they were planning, and so he could check that the plans fitted into the ethos of the Centre. Hence, the Centre demonstrated its willingness to support the Pioneers to implement their ideas, and Stephen offered my time to search for funding.

The outcomes of this work will be discussed in more detail in Chapter 6, and at this stage it is useful to deconstruct the steps that were involved in the Pioneers

reaching the point where they became informed decision-makers and could take control of the research agenda. An analysis of the data shows that there were four 'blocks of knowledge' that were needed so that the group could move from the position they held in sessions 1 through 3, to the position they held in Session 8 when they consolidated their decisions. The blocks of knowledge can be described as:

1. An understanding of The Holocaust Centre, its purpose and its facilities/programmes: these issues were introduced in sessions 1 to 5.
2. An understanding of how museums create exhibitions using different interpretive media: the work on this began in Session 2 and continued in Session 6 as the group began to understand these issues when exploring the main exhibition. It was deepened later in the project when the group visited the Imperial War Museum, as they were then able to compare the interpretive strategies at the Centre with another museum's Holocaust exhibition.
3. An understanding of the issues relating to disability access at the Centre: again, the group developed this knowledge through discussions about access issues at the Centre in comparison with access issues at the Imperial War Museum.
4. An understanding of the Holocaust and the disability history of the Holocaust: this history was introduced to the Pioneers during the first six sessions and in session seven the group met community artist, David Mayne, to start discussions about how to design a sculpture. They also attended an event at the Centre to remember the disabled people who were killed in the Holocaust.

It is my experience that when conducting community consultations museum staff often rush the process, putting people in the position of giving advice or making decisions without fully enabling them to understand the context of the museum. In the disability literature, Palmer (2000) indicates that there not enough training given to disabled people who are asked to consult on access issues in relation

to public services, and following Arnstein (1969) this type of consultation is tokenistic in nature. However, following Arnstein, within this action research the agenda was handed over to the Pioneers at the highest level of citizen control. However, it is interesting to note that their interaction with the Centre when implementing their ideas was at the level of partnership.

### ***Supporting the Pioneers to Implement their Decisions***

Once the Pioneers made decisions, the focus of the sessions moved on to support their implementation of them. In terms of the three strands of work that the Pioneers chose to focus upon (developing the sculpture project, advising on access issues and researching Holocaust issues), the youth workers and I focused on finding ways to support the Pioneers to put their ideas into action. For example, at the point that the Pioneers came up with the sculpture idea small-scale grants were available through Museums and Galleries Month. After consultation with the Pioneers, I was successful in bidding for £3500 to pay for them to work with a community artist to develop their ideas into a basic design. This design would enable the group to develop their sculpture idea to the point where it was feasible for them to put in a larger grant application to the Arts Council, to pay for them to work with an artist to create and install the sculpture at the Centre. In Session 7, the community artist, David Mayne, visited the group to meet them. The purpose behind this session was for the Pioneers to meet David to find out about his work and to tell him their ideas. The session was effectively an informal interview to assess whether David was able to support the Pioneers to realise their concept, rather than take over their vision. During the session he demonstrated that he had worked in an empowering way on

previous community projects. If his approach had not matched the way that the group worked, Margaret would have continued to invite other artists to meet with them. However, as David built up a good rapport with the Pioneers and listened carefully to their ideas, the Pioneers decided that they wanted to work with him.

The group began to work with David on their ideas for the sculpture in a further five sessions, between sessions 16 and 22. The sessions involved practical activities, with the group learning the skills that would be needed for the creation of the sculpture, such as clay-modelling techniques. There were also discussions about how to represent the disability history of the Holocaust. The group found these conceptual issues difficult to verbalise, so at each session David listened to their ideas and brought along drawings or scale models to the next meeting as visual aids. At each session he incorporated images that the Pioneers brought with them, drawings John had produced (as he was a talented artist), elements from their discussions and visuals from the clay work that they produced.

As figures 30 to 37 show, David helped the group create a design for the sculpture by incorporating their ideas into 2D designs and 3D models. The group critiqued his design and discussed the issues that they thought were important to emphasise or communicate, and then David worked on them to create further designs. There was an emphasis on practical activities to help the Pioneers expand and express their ideas. This approach was developed as a result of the group's initial difficulty in envisioning their ideas in Session 16, as the sculpture seemed too abstract. In particular, it was difficult for the Pioneers who had cognitive, developmental or learning impairments to focus upon these issues. Therefore, a more practical way of working was developed.



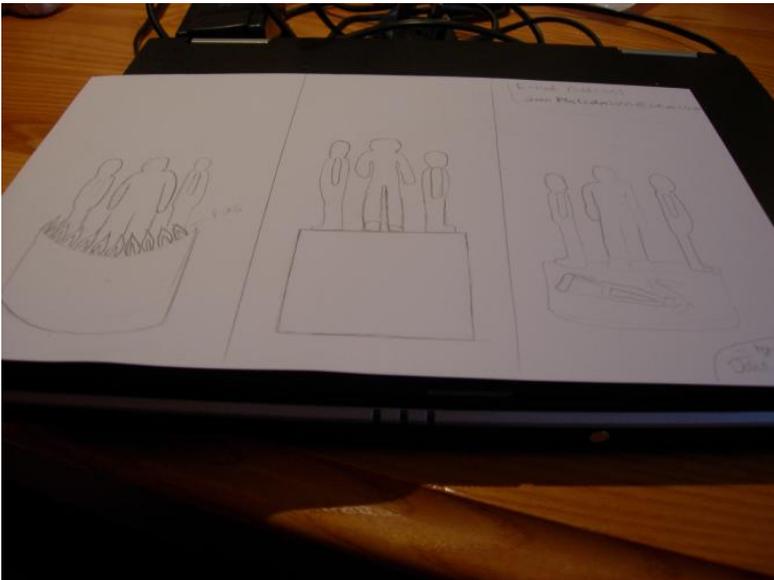
**Figure 30: Collaborative design process. In Session 21 David is showed the design that he had created in response to the issues discussed in Session 16**



**Figure 31: The group critique the design. They discuss how they like the idea of a plinth but not the flames, as they want disabled people to be represented in the sculpture**



**Figure 32: John contributes through his drawings. In response to this discussion John drew some visuals which responded to the issues the group were discussing**



**Figure 33: John's drawings. John incorporated disabled people into a design with a plinth, and David took these ideas from the session to create further drawings and a scale model**



**Figure 34: 3D model.** By Session 22, David has worked these ideas into new drawings and a scale model, and the group discussed how the figures did not look like disabled people



**Figure 35: Practical activity.** In a practical activity the Pioneers stood in a circle to show how people with different impairments could be incorporated into the design. Kerry joined in by taking photographs for the group



Figure 36: Clay modelling. The group then used clay to model shapes and words to give ideas for images that might be represented on the plinth

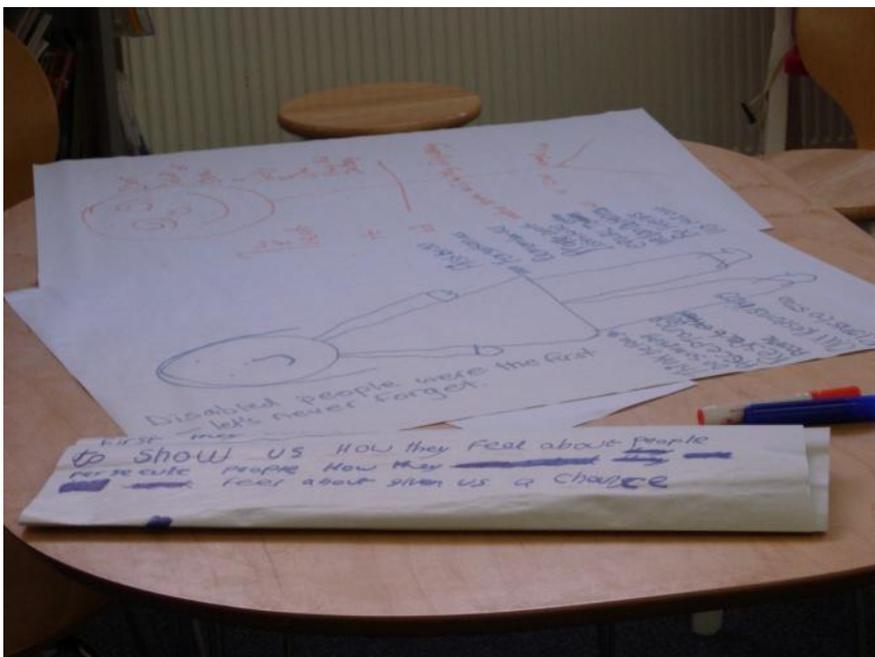


Figure 37: Brainstorming ideas. In another activity the Pioneers brainstormed the message that they wanted to include in the sculpture to represent what it means

The idea behind this relationship was that the artist would share his knowledge of the process of designing and creating a sculpture, with the Pioneers' ideas being placed at the forefront of the discussions. David was able to mirror Barnes's (1992a) assertion that researchers should place their skills and knowledge at the disposal of disabled people, although in this context it was an artist's, rather than a researcher's knowledge/skills. David also made no attempt to take over the agenda, as his aim was to support the Pioneers to create their design and implement their ideas in ways that were supportive of their impairments and access needs.

### **Development of Group Advocacy Skills**

In the past, the Pioneers had access audited organisations, but had not worked with them to implement their suggested changes. This project thus built on the advocacy skills that the group had already developed and took them a stage further. Reflecting back on Session 2, the Pioneers showed that they were already familiar with touring a venue and giving advice on the access barriers. In this session they audited the memorial hall and the main Holocaust exhibition. They created a written list of identified access issues and recorded them through photographs. They were already confident in voicing their opinions within the group. However, to influence change at the Centre the group needed to move beyond articulating and reporting on access barriers, to influencing the organisation to make changes. This involved the development of a wider range of skills in order to make their voices heard. An analysis of the data shows that this involved the Pioneers developing questioning and listening skills, negotiation and persuasion skills, presentation skills, assertiveness and self

confidence. They developed questioning and listening skills throughout the sessions as they asked questions about the project and debated issues. One important issue was that the Pioneers needed to gain confidence and assertiveness, in order to challenge the senior management of the Centre to understand the access issues built into the Centre, and develop ways to avoid these problems reoccurring within the new exhibition. To gain this confidence the group initially voiced their opinions to me during sessions when we toured around the main exhibition, the memorial gardens and the facilities (sessions 2 and 5). As Margaret and Pam were unable to go down into the main exhibition, due to the broken stair lift (they both have physical impairments and cannot easily use stairs), the group also articulated the issues that they had identified to Margaret and Pam. The Pioneers therefore initially voiced their concerns within the group, and during sessions 6 and 7 they moved on to articulating their views with visitors to the group. In Session 6, Sarah Moore, ICT disability research specialist, visited the group to talk about blogging, and in Session 7 they met David Mayne, the community artist. The Pioneers guided them around the Centre and showed them the issues that they had identified. As the Pioneers learnt more about the Holocaust and access issues in the museum context, they gained confidence in the validity of their views.

This helped prepare them to meet with Stephen Smith who, as Chief Executive, was managing the staff team working on the Centre's refurbishment and the new exhibition. In preparation, the group worked together to create a PowerPoint presentation that explained why they wanted to support the Centre, and identified the issues that they had decided to work upon. On the evening they met Stephen (Session 12) they gave him a tour of the Centre, and spent

over an hour showing him the access issues that they had identified. This was an illuminating experience for both parties. At times, Stephen seemed visibly uncomfortable when the Pioneers pointed out inaccessible features and explained their consequences. The following conversation is representative.

Laila: You see this here. These small plaques, they just don't work for us. I have Dyslexia and they make my eyes swim. When I look at them I start to feel dizzy and have to look away. It's all the white on green and that small writing.

Stephen: Okay... I see.

Laila: If you've got what I've got then all these small plaques, and all the writing, it means you switch off and miss loads. I don't mean to be rude, right, but it could be more accessible.

Stephen: So what would work better for you?

Lorraine: Audio. Tell him about the audio, Audrey.

Audrey: Well, I think you can say something about it, go on, Lorraine.

Lorraine: Less writing's better. I seen when museums 'ave these audio thingies. Walk round with that, tell you 'bout it.

Stephen appeared uncomfortable as Laila explained the consequences of the interpretive decisions that the Centre had made (see Figure 38, which shows the small green plaques with white writing and the tiny fonts that Laila identified in the conversation above).

In return, Stephen explained some of the issues that his family had faced when putting together the exhibition on a 'shoestring'. For example, he explained that some of the videos were made on an old video recorder in James Smith's



**Figure 38: Interpretative panels in the main exhibition**

bedroom the night before the exhibition opened, as they could not afford to get a professional company to edit the footage they had obtained. He talked passionately about the way they put the Centre together with the aim to tell the stories of the people who were affected by the Holocaust. He discussed their lack of experience in creating exhibitions, and some of the difficult choices they had to make about what stories to include in the limited space available. This gave the Pioneers a greater insight into the complexities involved in creating the Centre. Stephen was also visibly moved by the commitment and interest of the group.

At the end of the exhibition everyone stood for a moment in silence, looking at the broken stair lift before commenting on the inadequate nature of its design:

John: I was... was just shocked the first time I saw this.

Laila: Yes. I don't mean to be funny or anything but this doesn't even go down all the way.

Keiron: Doesn't work, neither.

Lorraine: Pam 'n Margaret never been down 'ere 'ave they. Never been.

Audrey: Yes, Pam and Margaret can't get in without the lift.

Stephen: Yes, this was a large mistake. We relied on a stair lift company to tell us what the best option was, and it seems strange now looking back that we didn't question them. We just relied on their advice.

Laila: But really, couldn't you see it wouldn't work?

Stephen: Well, it seems obvious now that it doesn't help people get into the exhibition, but we weren't thinking like that.

Here we can see the group confidently and assertively highlighting a piece of poor access, and holding the Chief Executive to account for the decision made over its installation. This meeting made a large impression on Stephen. In his interview he made the following comments.

It's been a vital part of the development of *The Journey* that we've had a reference group to run designs past and get feedback from. In the main exhibition we built all sorts of inaccessible features in without thinking. The Pioneers have made us stop and think, think about what we're doing and whether it's accessible. This has been a big shift for the organisation, and for me.

By directly advocating their views in a confident, informed and assertive way, the Pioneers were able to make a considerable impression on the Chief Executive. In return, they understood more about the issues behind the inaccessible features, giving them a greater insight into the organisation.

In her interview, Margaret explained why it is important for the Pioneers to develop advocacy skills:

sometimes our young people don't have a voice. They're being bullied at school or their families think they know best. We help 'em to know their rights and choices. It's important they develop skills to speak up for what they want and need.

This echoes Boylan and Dalrymple's (2009) views that the development of advocacy skills is important to support young people with the transition to adulthood. Therefore, the development of these skills was not only important to support the Pioneers to achieve their aims, but could potentially have a wider benefit in their lives.

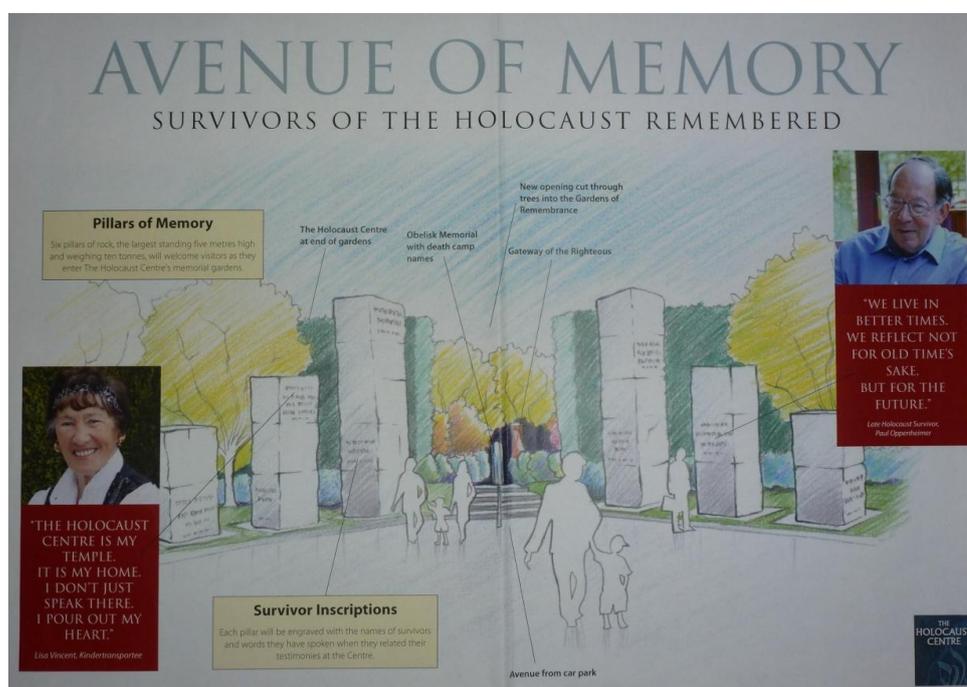
The most useful guidance on supporting people to develop advocacy skills comes from guidance to practitioners. For example, The United Nations Development Programme (UNDP) 'Learning and Information Pack' was created to support professionals and volunteers working in Gender Development Programmes to understand the processes involved in advocacy work (UNDP 2001). Although this pack focuses on issues relating to gender, the advocacy skills it outlines are equally applicable to disability advocacy. The pack breaks down the skills that individuals need to develop to be effective advocates into: listening; questioning; decision-making; presentation; facilitation; brainstorming; summarising and assertiveness. These are in addition to the ability to work as a team to influence change. This range of skills mirrors many of the skills that the Pioneers developed during the action research.

## Implementation of the Emancipatory Principles

The principles that should underpin the planning and implementation of emancipatory research were explored in Chapter 4. As discussed, they were developed in response to the historical exclusion of disabled people from the research process (Hunt 1981; Oliver 1990; 1992; Abberley 1992; Zarb 1992). As outlined in Chapter 4, the key principles of emancipatory research involve empowerment, reciprocity, gain, involvement of disabled people in the research process, reflexivity and reflectivity, loss of neutrality and objectivity, control of the research agenda and accountability to disabled people in relation to the way that the research is planned, conducted and analysed. When looking at these principles it is clear that, although the majority of the principles refer to the way that research is implemented, the issues of empowerment and gain relate to the outcomes of the research. Therefore, these two principles will be explored in Chapter 6, along with the other outcomes identified in the data.

**Reciprocity:** Oliver (1992) talks about the development of a reciprocal relationship between the researcher and the people involved in the research, where they build a relationship based on trust and respect. As previously discussed, both the Pioneers and the youth workers needed to know that I was genuinely committed to working with them. In Audrey's interview, she confirmed that I was able to become a member of the group, saying 'and now you're one of the group and when they talk about it it's us and Heather. [...] You know, everything is including Heather [...] you're part of it now'. In her interview, Laila discussed the reciprocal nature of the relationship that developed, saying: 'Cause I think that you want our help as much as we want yours. We're on the same wave-length'.

Trust developed as the group started to see that when they raised an issue they had an influence on the Centre. An early and important example of this for the Pioneers was in relation to the development of the Centre's new car park. Initially, one of the Centre managers championed a design that included steps from the car park into the memorial gardens (see figures 39 and 40). The new car park was deemed necessary to accommodate the additional visitors who would be on-site when *The Journey* exhibition was launched. In Session 9 the group viewed the designs and voiced their concerns that the steps would prevent disabled people from entering the site in the same way as other visitors, and that the planned accessibility route would take them on a long journey behind a set of trees. This meant that the people who had the most access needs would have the longest journey to get to the Centre.



**Figure 39: Photograph of the draft design for the 'Avenue of Memory', a route to take visitors from the car park into the Centre's gardens**



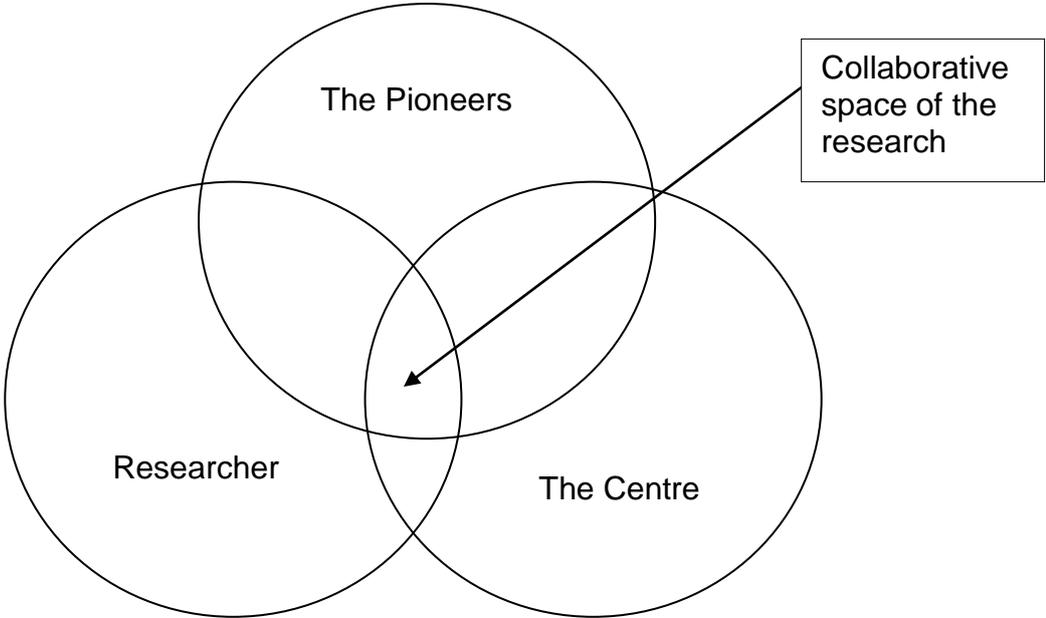
**Figure 40: Enlarged image of the design to show the planned steps**

I took the Pioneers' concerns back to a staff meeting on the issue, and with the intervention of Stephen Smith the plans were altered and an accessible design was chosen (see Figure 41, showing the Pioneers celebrating the installation of the accessible solution in Session 16).

At the start of the project I had anticipated that a reciprocal relationship would develop through collaboration between the Pioneers, the Centre staff and I (see Figure 42). However, the actual relationship that developed was somewhat different. As previously discussed, it took time for the staff to understand that my role involved more than 'policing' access issues and advising on technical matters such as the door widths appropriate for wheelchair users. In my professional role at the Centre I focused on a process of organisational change to develop staff understanding of disability issues and to persuade them that everyone had a responsibility to prioritise these issues in their work.



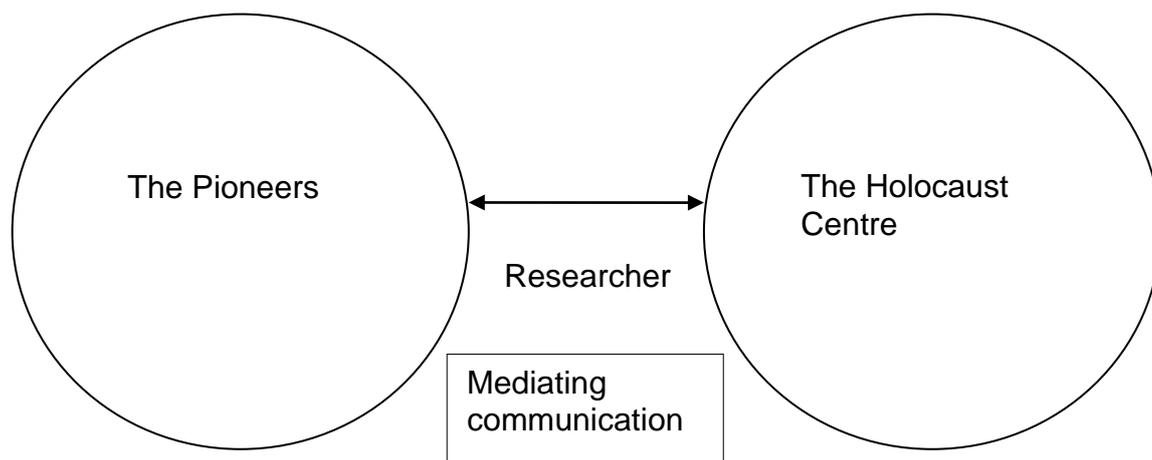
**Figure 41: Pioneers standing on accessible path (from left to right: Margaret, Laila, Lorraine, Audrey, John and Keiron)**



**Figure 42: Anticipated relationship between the Pioneers, Centre staff and researcher**

I realised quite early on in the project that I needed to alter the approach that I had envisaged, as there were development issues for both the Pioneers and the Centre staff. The Pioneers needed support so that they could develop their own aims for the action research and learn the skills needed to become effective advocates. The staff in turn needed to be ready to listen to the issues that the Pioneers wanted to raise.

Initially, I acted as what is described in the literature as an 'audience advocate'. Reeves (2006) discusses how staff can become advocates for particular audiences. Reeves (2006) and Samuels (2006) both state that this role is often fulfilled by staff within education departments or specific access officer posts. Furthermore, Reeves (2006) describes how advocacy is a crucial concept in the development of museums that are responsive to their audiences, and Samuels (2006) calls for the whole organisation to be collectively responsible for access issues. She also outlines how access specialists within staff teams can support wider teams to think in a more accessible way. Often, the aim of this type of post is to support excluded communities to have a voice within the organisation and to challenge inequalities. As is apparent from the example of the car park design, this definition describes my role at the Centre as I mediated the relationship between the Pioneers and the Centre (see Figure 43). However, this was not an ideal position to be in, as to all intents and purposes I was in control of representing their point of view. When reflecting on the implementation of the research, one concern in the early stages was that if I brought the Pioneers into contact with the Centre staff it would be a negative experience for them, as early in the process key members of the staff were not ready to listen to the group.



**Figure 43: Mediation role between the Pioneers group and the Centre**

My aim was to gradually support the Centre staff to understand more about disability access, whilst challenging them to include these issues in their working practices. By the end of the project, the Pioneers and the Centre staff had started to develop a relationship, as the Pioneers had met both James and Stephen Smith, and a significant portion of the staff had attended disability awareness training. This took place in advance of staff working alongside the Pioneers on an event on 11<sup>th</sup> May 2008 to remember the disabled people who were killed during the Holocaust, and to dedicate a plaque and rose in the gardens to this community (see Figure 44). The programme included a range of speakers, notably disabled artist Alison Lapper and Liz Crow, a disabled film maker who was making a film about this history. On this day the Pioneers worked alongside the Centre staff to deliver the event. For example, Keiron was paired with a member of the administration/finance team, and they worked together to ensure that disabled visitors who arrived at the event by car would be allocated suitable parking spaces. John greeted people arriving at the event

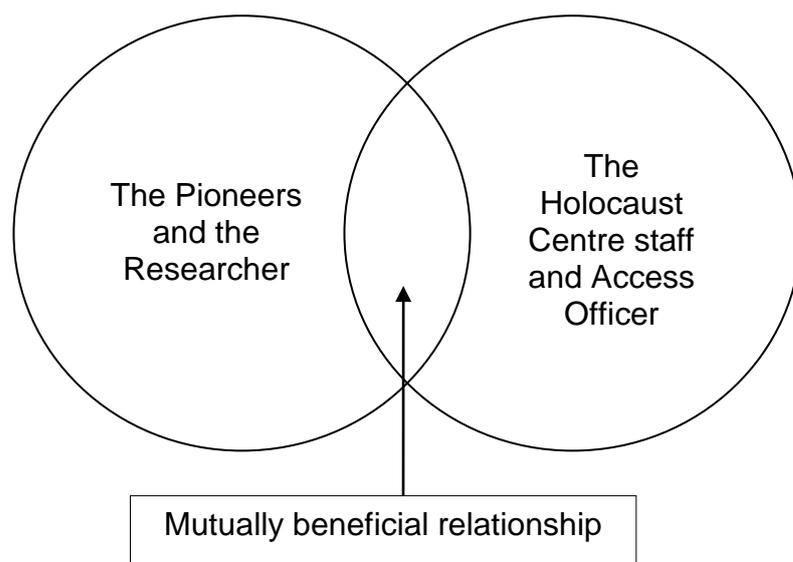
alongside James Smith, and Kerry helped staff from the education team on the reception desk to register people on arrival.



**Figure 44: Pioneers at the disability event. Sian, Kerry and Laila placing the plaque in the gardens under the gaze of the local and national media**

These opportunities brought the staff and the Pioneers' relationship closer together. Figure 45 reflects the development of this relationship, showing my status as an insider as a member of staff at the Centre and as a member of the Pioneers' Holocaust sub-group. It also represents how, although the parties had started to work together, they were still reliant on my mediation role. In Chapter 6 the analysis will focus on whether this development was enough to support the Pioneers to influence change at the Centre.

My approach was to mirror the techniques of the youth workers to support the Pioneers to achieve their aims, and to support the development of a mutually



**Figure 45: The relationship between my dual role (researcher/Access Officer), Pioneers and Centre staff that developed by the end of the project**

beneficial relationship with the Centre. Also important, as discussed in the disability literature (Barnes 1992a; Kitchin 2000), was the placing of the embodied knowledge that the Pioneers had of living with impairments on an equal footing with the knowledge that I had about museums and the research process.

**Reflexivity and reflectivity:** Being responsive to the Pioneers' needs was a really important aspect of ensuring the long-term viability of the action research. Bewley and Glendinning (1994) discuss how logistical details and access issues are an important consideration when planning fieldwork. We met in the café, which was the most accessible part of the Centre. As noted earlier, the session time was changed to a Monday evening to ensure that the Pioneers could attend the sessions. As stated by Pam in her interview, it was unusual for the Pioneers to commit to a long-term project: 'It's got to be two years. And that's quite a jump for youth work, that historically they'd lose interest after a month or two and say we're not going anymore'.

From Session 5, in response to concerns that the Pioneers raised we started to move into a more active phase of the project. In her interview, Pam discussed this moment in the project:

And we realised we [needed to] give them ownership of it. The only way to do that was to say okay what do you want to do next? Do you wanna keep coming here and doing this, or what? [...] If you're gonna do this, how do you want to do it? Or we were gonna lose them. [...] And it meant that it was time to give them power and responsibility for it, really.

Being responsive to the Pioneers ensured that they gained a sense of ownership of the research agenda. This responsive approach was applied throughout the project. For example, with the sculpture project, practical activities were created to help them shape their ideas, as discussions about the abstract issue involved did not work as an approach. Margaret described in her interview how the content of the sessions tended to be delivered in either a verbal, visual or practical way, so that the Pioneers could process information and learn together. Therefore, the approach to the sessions was continually adapted to support the Pioneers' needs.

**Politically motivated research and the loss of neutrality and objectivity:** In alignment with Oliver (1992), this piece of research was a political act, as it aimed to support an oppressed group to challenge power inequalities in the research process and the museum context. It was therefore conducted from a subjective position. However, there were unforeseen difficulties in this position. First, joining with an oppressed group (as described by Barnes 2003b) meant that I became invested in them as a group and as individuals. I developed a close relationship with the group and at times felt concerned about the lack of commitment that some Centre staff to addressing access issues. Initially, as

some staff were openly sceptical about the need to do more than meet the minimum legal requirements under the DDA (1995), I did not want to expose the group to their negative views. I felt concerned that if they came in contact with some members of the staff the Pioneers would become demotivated and demoralised. Therefore, I was concerned about the emotional effect that working with the Centre would have on them.

When looking at the literature, in retrospect there were times when I avoided what could be argued was 'necessary conflict'. Lynch and Alberti (2010), in their candid analysis of the 'Myths About Race' project that The Manchester Museums engaged in with the local black community (as part of the Bicentenary of the Abolition of Slavery), reflect on how staff on their project avoided conflict, and thereby suppressed the politics of the process, which meant that issues of the museum's institutional authority were not challenged. They considered how this led to the participants' disillusionment, and an erosion of trust. In hindsight, perhaps I should have brought the Centre staff into more direct contact with the Pioneers earlier in the process. However, unlike The Manchester Museum project, as the Pioneers saw that the Centre was responding to the issues that they raised, trust was not eroded.

The concern that I felt about the Pioneers being negatively affected by the Centre staff attitudes arose as a result of the subjective position that I occupied in the research project. In their publication 'Emotions and Fieldwork', Kleinman and Copp (1993) raise the question about whether researchers admit that they are attached to the people that they are researching. In the context of this study, I developed a close bond with the Pioneers and was very aware of the

vulnerable and sensitive nature of some members of the group. Consequently, at times I became a gatekeeper rather than a mediator.

**Control of the research agenda and accountability:** A disability organisation did not commission or fund this piece of research, and I decided on the focus for the study, therefore, disabled people were not totally in control of the overall agenda. However, as this chapter has demonstrated, that the Pioneers were supported to take control of the research agenda, which was a central aim of the study. Barton (2005) states that disabled people should be in control of the planning, implementation and dissemination of research. The Pioneers were given the opportunity to be involved as co-researchers and to get involved in the data collection process, however, they chose not to be involved in this element of the project. As Mercer (2004, 11) notes: 'Not [...] all disabled people have the time or inclination to take over control of the research production', and the Pioneers were also not interested in matters of analysis or dissemination. As Barnes states 'accountability is a major consideration for all those striving to do emancipatory disability research' (2003b, 7), and the direction that the research took was led by the Pioneers. Additionally as discussed in Chapter 4, Margaret Clement was interested in supporting the analysis to ensure that the Pioneers' work was represented in an appropriate way, therefore the study has remained accountable to the group. Margaret and I are currently in discussions about how the methodology that was developed during the action research could underpin the development of a new arts performance group that the DST are developing.

## Conclusion

This chapter has discussed the process of undertaking emancipatory disability research at the Centre. It aimed to deconstruct the process of implementing the emancipatory principles, and the data has highlighted four broad issues as being key to the process: team building; the Pioneers achieving informed decision-making; the development of advocacy skills; and the Pioneers taking control of the research agenda. The Pioneers gradually developed a mutually beneficial relationship with the Centre, and they gained confidence in their ideas and in their advocacy skills as they witnessed visible changes to the site and facilities. At times, this process was challenging because the Centre staff were not necessarily committed to disability issues and this meant that, initially, I acted as an 'audience advocate' to mediate the communication between the Centre and the Pioneers.

A variety of authors have questioned whether emancipatory research is an achievable goal for researchers (Oliver 1997; Barnes 2001). Overall, it can be argued that I was able to follow the majority of the principles involved in conducting emancipatory research. This study was able to go further than some studies (Bennett 2002; Petersen 2011) in adhering to the principles. However, it can be argued that Priestley's (1997) PhD study fulfilled elements that this study has not been able to achieve as the focus for his research was crafted in consultation with disability organisations. Other studies such as Dowse's (2009), also involved disabled people more centrally in the collection and analysis of data. However, overall it was an achievement to have followed the principles so closely due to the multifaceted nature of their implications. A significant factor in

this implementation was the large overlap between these principles and the working practices of the youth workers.

## **Chapter 6: Impact and Outcomes of the Research**

### **Introduction**

This chapter investigates the impact of the research and the outcomes for the Pioneers, the youth workers, the Centre staff and the organisation (the impact on my own practice will be discussed in the concluding chapter). It details the extent to which following the emancipatory principles supported the self-empowerment of the Pioneers, and how they benefited from their involvement. Looking back to the issues raised by Freire (1972) and Solomon (1976) in relation to empowerment, the analysis will examine how the staff were influenced by the work of the Pioneers, and the extent to which this affected their working practices. In terms of the Centre, it will explore the factors that had a bearing on whether the organisation moved forward toward becoming an inclusive and equitable place, and what influence the Pioneers had on the changes at the Centre. The analysis draws on issues of participation (Simon 2010) and power-sharing (Lynch and Alberti 2010; Lynch 2011a) to establish whether the Pioneers, as an external group, built the social capital needed to exert an influence over the Centre.

### **Outcomes of the Pioneers' Aims**

As discussed previously, the Pioneers developed three aims for the focus of their work:

1. To create a sculpture that represented the disability history of the Holocaust.

2. To advise on access issues within the new exhibition and the wider site refurbishment.
3. To research into the Holocaust, the disability history of the Holocaust and accessible museum interpretation.

Before analysing the outcomes of the research for all the parties involved, it is important to explore whether the Pioneers were able to implement their aims.

### ***The Sculpture to Represent the Disability History of the Holocaust***

The group worked with the community artist over five sessions to develop their ideas. At the end of this process they had a working design and, with his support, they understood the processes involved in creating, installing and interpreting it. They explored the disability history of the Holocaust through newspaper articles, Internet research and by their involvement in the Centre's event which remembered the disabled people who were killed during the Holocaust. The speakers at this event enhanced the Pioneers' understanding of this history, and this new knowledge influenced the design of the artwork. In Session 11, the Pioneers worked with Margaret and I to fill in the sections of an Arts Council grant bid that represented their views on the project. At the point that the research was completed the form had been submitted to the Arts Council for consideration.

### ***Advice on the Centre's Refurbishment and The Journey Exhibition***

The Pioneers advised on issues of accessibility throughout the development of the refurbishment and the new exhibition. Their input was instrumental in creating an accessible interpretive approach in *The Journey* exhibition, which will be described later in the chapter. They were also able to view the outcomes

of their advice during the installation phase, and were invited to the main launch event. This was significant as they were the only non-Jewish group invited to the launch, which reflected their status as valued stakeholders alongside the Holocaust survivors and Jewish organisations that attended.

During the development phase they advised on access issues in relation to the refurbishment of the reception, café, signage and car park. £15,000 was additionally raised to improve the main exhibition. Although the donor who gave this money placed an emphasis on the need to 'cosmetically' improve the main exhibition so that it did not look so 'tired' in comparison to the new exhibition (it was over ten years old), access improvements were also built into these plans.

### ***Research into the Holocaust and Accessible Museum Interpretative***

#### ***Techniques***

Alongside their independent investigations into Holocaust issues, I shared my knowledge of the Holocaust and accessible museum interpretation with the Pioneers. In addition to this, they also organised a visit to the Imperial War Museum, where they viewed and critiqued its Holocaust exhibition. This experience allowed the Pioneers to explore alternative approaches to interpretation of Holocaust issues, and created a point of comparison with the interpretive approach at the Centre. As will be discussed later in this chapter, they encountered additional access barriers in this exhibition, which surprised them as it was clear from their interviews that they thought a national museum in London would be a paragon of best practice. Laila for instance, thought this museum would 'show The Holocaust Centre how it should be done'. Having a point of comparison enabled a wider discussion about accessible museum

interpretation to develop, and from this visit they gained a greater understanding of the complexities involved in trying to make different interpretive techniques accessible.

Although empirical data was not gathered after the project was completed Annex 1 explains what happened after the research ended to give a broader, albeit anecdotal, perspective on the longer term changes for the Centre and the Pioneers.

## **Outcomes and Impact of the Research for the Pioneers**

When analysing the data, the impact and outcomes of research can be organised into two broad headings. First, the Pioneers gained an increased conceptual understanding of issues relating to disability, and second they directly benefited from the research due to their involvement. Both of these outcomes contributed to their self-empowerment which can be seen as the overarching impact of the project.

### ***Increased Conceptual Understanding of Disability Prejudice***

One of the unexpected issues that arose from the data analysis was that the Pioneers gained a greater understanding of the prejudice that surrounds disability today by exploring the past. Conversations about who might be perceived as disabled, the issues that still affect disabled people, and the connections between these issues and the ways that disabled people were treated in the past were discussed throughout the project. During the course of the sessions, a range of issues were discussed: Laila raised the issue of 'Ashley

X' in the USA, which was in the news at that time. As discussed in the last chapter, in this high profile case a child with severe developmental impairments underwent surgery and hormone treatment to prevent her from entering puberty. It raised ethical issues about the rights of disabled children over their bodies. When discussing the access audit, the group debated whom we would consider to be disabled and what this 'umbrella' term meant. During one of the sculpture sessions, Margaret discussed the social model with the group in response to Keiron expressing an opinion about disabled people being objects of charity. He had clearly internalised some of the negative messages about disabled people needing to be pitied. Margaret also discussed a case of a young disabled person in Mansfield who had been a victim of a disability hate crime.

In their interviews, Margaret and Audrey discussed how these complicated issues of prejudice, disabled people's rights and status within society were able to surface due to the subject matter of this study. As the Pioneers learnt about the disability history of the Holocaust and its origins in the prejudices of the Nazi regime, it enabled complex conversations to develop. In both John and Lorraine's interviews, they made connections between the ways that disabled people were treated in the past and contemporary issues of prejudice. For example, Lorraine discussed why she thought that the sculpture project was important:<sup>29</sup> 'To say what happened to disabled people and for memory of them, to remember what happened to them [...] and what we're treated like today'. She went on to explain that people did not always treat her as well as she would like, and that people needed to 'Listen to us, hear us more [...] So we've got a disability, if we need some help, they have to help us'. Discussing the treatment

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<sup>29</sup> Lorraine has a speech impediment, so her ideas are not always expressed in full sentences.

of disabled people in the past enabled the Pioneers to place some of the issues that they encountered in their own lives into a wider historical and social context. The youth workers perceived this as a positive outcome of the project. As

Audrey explained:

I think the differences is they're becoming more aware of other people's prejudice around them.[...] that the prejudice that happened a long time ago was worse than [...] they feel it is today. But they're still aware that it's happening today because they now bring [...] paper cuttings from the newspaper and say, have you seen this? In fact, last night at the meeting they was talking about the lady in Nottingham that was refused to go in a swimming baths because she was in a wheelchair. [...] The baths were disabled friendly but they couldn't get through the door. [...] So they brought that with them to show us all about it. Where at one time that wouldn't have entered their heads to think about that.

So, by having a greater awareness of disability prejudice in the past, the Pioneers became more aware of contemporary issues of prejudice. This allowed them to raise issues that they identified with the help of the youth workers. In her interview, Margaret showed how an awareness of how the disability history had enabled some of the Pioneers to think about issues that were occurring in their own lives:

I think the subject area enables us to talk about things that probably they wouldn't always have conversations about.[...] I think by understanding the history of disabled people and their experiences in the past enables us to see what's happened today and can alert us to inappropriate behaviour around people, and what's not appropriate, and like the sterilisation thing [referring to the 'Ashley X' case] but also the experimentation [...] it's very easy to say to people, shall we try and straighten your arm out? [...] Not necessarily to improve their quality of life but very often to make them look more normal.[...] Because society's more comfortable when people don't look different, so if they don't look different they're more accepted, and sometimes for the young people there is all sorts of questions about that. Again, one or two of the group that come to The Holocaust [Centre] are having those conversations with medical staff about do I go down this route of having [a] medical intervention of some kind? [...]. And I think by understanding why are they doing it, is it to improve the quality of their life or is it to make them fit in more?[...] More knowledge means that you can make an informed choice.

[...] So giving young people a broader perspective on their past and also seeing some of the positives about where they are now. [...] And that things have moved on from the past, but never losing sight of the fact that it could quite easily slip back into that if we're not too careful.

As Margaret discussed, through the project the Pioneers gained a greater understanding of historic medical interventions such as sterilisation, and how these issues resonated in their own lives. Understanding how these medical interventions can sometimes not be about quality of life issues, as they are related to issues of 'aesthetic normalisation', provided the Pioneers with greater knowledge about the options available to them, and therefore a greater appreciation of the choices available. Thus, by exploring the disability history of the Holocaust and applying what happened to disabled people historically to situations in their own lives, rather than the events becoming a disturbing and negative experience, it gave them a sense of context for complex discussions. Margaret went on to explain why it became important that the project had a dual focus on disability history whilst investigating access issues at the Centre:

I think because we've been doing two things side by side, they've been able to bounce about between the two. So because we've been doing some positive development in terms of access, and they can see that by them having a voice, and being able to contribute, has actually improved something that other people will be able to benefit from, then you can almost say it's easier, then, to deal with who you are and what has happened historically, and how that affects your life, because you're dealing with a positive and a negative at the same time.

Looking back on the literature on oppression resonates with Freire's (1972) ideas about 'liberatory education'. As discussed in Chapter 1, Freire's 'liberatory education' involves a series of concepts that include 'conscientization', 'praxis' and 'dialogue'. He argues that oppressed people need to 'undergo changes in their consciousness so that they understand that they are oppressed and can

act to change their situation' (Coben 1998, 53). For Freire (1972), conscientization represents the awakening of critical awareness, and involves an understanding of the way that society oppresses people, and the consequences of that oppression. The data provided evidence that the Pioneers had gained such a much greater understanding of contemporary issues of disability prejudice and its context within a wider history.

Freire (1975) also believed that there is a relationship between the knowledge of a person's reality and the work needed to transform that reality. He claims that this can be achieved through a pedagogy of problem-posing education. I would argue that this process went on during the Pioneers' sessions. The Pioneers deepened their understanding of issues relating to prejudice and the exclusionary practices that were creating barriers to access at the Centre. By achieving the position of informed decision-makers, leading the research agenda and finding ways to implement their aims, the Pioneers took control and became the agents of change. This is of interest as, although the museum literature discusses museums acting in the role of agents of social change (Sandell 1998; 2002a; 2003; 2007; Silverman 2002; Janes and Conarty 2005), it does not focus on how museums can support people from oppressed groups to enact change in their own lives. In alignment with Freire, in this study the act of creating change, both at the Centre and in the Pioneers' own lives, involved much debate and problem-solving, as the solutions to the issues that were raised were not always straightforward. For Freire (1972), conscientization is followed by praxis and dialogue, which involves a process of reflecting on the situation in order to transform it through action. Again, I would argue that this is what occurred during this project. The Pioneers reflected on the reality of the

situation at the Centre and, armed with increased skills, were able to act on their aims and work to change the situation.

### ***Benefits of the Pioneers' Involvement in the Research***

There were numerous benefits discussed by both the Pioneers and the youth workers in relation to the young people's involvement in the research. Overall, these benefits can be described as the deepening of their advocacy skills, their increased capacity to work as part of a team, the development of life and employment skills, a sense that they were making a difference through their work with the Centre, an increased sense of their own agency, an increase in their self-esteem, and a sense of pride developed through their involvement in the project. These outcomes are in accordance with Newman, McLean and Urquhart's (2005) study, which indicated that museums have great potential to support socially excluded people to develop greater confidence and self-esteem, and to learn transferable skills to support them to tackle issues which contribute to their exclusion.

For different members of the Pioneers, different aspects of the project were important. For example, John was a talented artist, and for him the development of artistic skills as part of the sculpture project was of great benefit. For Lorraine, the greatest benefit was her increased ability to work as part of a team, which she indicated was a challenge at the start of the project. It can be argued that in relation to community projects which aspire to reciprocity, there is a need to create a diverse range of opportunities for people to engage with during a project, as people will come to the situation with different life experiences, aspirations and needs.

## ***Deepening of Advocacy Skills***

Chapter 5 discussed the Pioneers' development of advocacy skills. The facets of advocacy they developed were described as a development or deepening of questioning and listening skills, negotiation and persuasion skills, presentation skills, assertiveness and growth in self-confidence. The culmination of these skills was the meeting with Stephen Smith, where they confidently showed him the access barriers that had been built into the Centre, and advocated for change. In the interviews with the Pioneers and the youth workers, both parties reflected on the impact of the development of advocacy skills, both for the group and for individuals. Pam discussed the impact of the group witnessing the outcomes of their advocacy at the launch event:

Well in terms of results, the opening day speaks for itself. [...]. They saw everything had come together and they were able to see the changes. That had gone really, really well, what they've been taken notice of the car park and signage, all sorts of things all came together in one day. They were commenting on that all day, isn't it different? [...] We've helped them see they can do it. [...] We've helped them see they've got a voice.

Viewing the visible outcomes of the advocacy process was important for the Pioneers, as it gave them tangible examples of how their voices had been heard. They were able to tour the updated facilities and the new exhibition and see their impact on the Centre. As Pam explained, this encouraged them to understand that when they advocated for their opinions, changes did occur. For some of the Pioneers, being listened to and seeing the changes was quite astonishing. For example, Michael described his feelings as: 'Just shock. [...] honestly it was just shock. [...] I expected work not to develop that quick'. A similar view was expressed by Laila in her interview: 'I thought it might take longer. [...] But actually it's come on quite a way. [...] I thought it would take

years to be honest. Sometimes [...] the people want you to come and talk and then you'll go away and that will be it'. Laila and Michael's reflections indicate that they did not have initial confidence that the Centre would listen to them or act on their advice. Laila in particular appears to have been concerned that the Centre might just have been paying 'lip service' by inviting them to give advice. The impact of the development of advocacy skills was clearly articulated by Laila in her interview:

I've got more confidence, and I'm liking helping others. I don't know, it's just a nice feeling when you see something you've said that's been done. [...] Well actually they are listening to us. [...] I can see people more listening to me. They're not gonna like just blank me. [...] They are going to listen to what we have to say. [...] It makes me feel better in my life [...] I'm not going to be sat in the background. I am going to come forward.

Laila seemed to be indicating that her growing confidence and skills were transferable beyond the project to her daily life. When individuals are unable to advocate on issues that they consider important, this can lead to feelings of powerlessness, which Solomon (1976) asserts is a key contributing factor to oppression. Solomon states that power deficiencies stem from a complex and dynamic interrelationship between the person and hostile social relationships, and the way that this interferes with the process of human growth. In the context of the Pioneers, these young people were at an important transition in their lives. As described by Young (2006) adolescence is the transition between childhood and adulthood, when young people move from dependence to independence. As previously discussed, from Young's research this transition is more complex and difficult for young disabled people than for their non-disabled peers, due to society's low expectations of disabled people and a lack of focus on young people's abilities. At this formative stage, the opportunity to reverse the power

blocks that may prevent these young people from being able to negotiate power relationships is an important outcome for them. Solomon (1976) discusses empowerment in terms of the process of removing the power blocks that keep people in a position of powerlessness. The data show that for the Pioneers the development of advocacy skills led to a sense of self-empowerment.

### ***Increased Capacity to Work in Teams***

The development of a strong team was important to enable the group to explore complex and sometimes emotionally challenging subject matter arising during the project. For some of the Pioneers, the opportunity to work in a close team situation was important. It was one of the key life skills that the youth workers, Laila and Lorraine together identified as an outcome of the project.

At times in the sessions Lorraine's views were overlooked, as she could come across as quite hesitant. Her speech impediment affected her ability to voice what she wanted to say to others. However, the team-building process, coupled with the development of advocacy skills gave her more confidence to voice her views: 'Learnt how to working together, team work [...] getting on with everybody [...] getting your views out. [...] Because they're listening to us what we want'. In her interview Laila discussed another aspect of working in teams:

Heather: And do you think you've gained any new skills by the activities we've done?

Laila: Yeah, like more team building and how to work with people better even if you're not very keen on them.

Heather: Right, so people that you sometimes find a bit difficult.

Laila: Annoying.

Heather: So how have you found yourself change then; what's changed?

Laila: You just, like, get on with it. You put that, your differences aside.

Forsythe (2010) cites Tuckman's (1965) stages of team development to discuss how teamwork is not always a harmonious process. Due to the dynamic interplay between the different personalities within a group, at some point people will disagree, or find other people's behaviour annoying. However, part of successful team working is the ability to ride the 'storming' phase and learn to get along with others. The resilience involved in getting along on with others and the ability to work in teams are skills that are transferable beyond the project, and will benefit the Pioneers in a variety of situations.

### ***Development of Life and Employment Skills***

There is evidence from the data that the Pioneers developed a series of life and employment skills that had the potential to benefit them beyond the project. The development of advocacy and team building skills, which could be argued are also life and employment skills, have already been discussed. The development of organisational skills was a feature of the early sessions. For example, at the end of Session 1 there was a long discussion that lasted 36 minutes to help the Pioneers to find a common date for the next meeting and, for them to all record it in their diaries or on their phones. They also discussed how they were going to get to the Centre, located in the middle of rural Nottinghamshire with poor transport links. For some of the Pioneers, organising their time and arranging transport were an important developmental issues.

Although the project did not primarily aim to focus on specific skills to support the Pioneers' future aspirations for employment, it is clear from the Pioneers' and the youth workers' interviews that the project contributed to the gaining of skills to support their career aspirations. For example, John's opportunity to work with the community artist bolstered his confidence in his abilities, and he benefited from being exposed to new ways of thinking about art and new techniques. Pam reflected on John's development in her interview:

I think John has grown because he was given the opportunity to platform his artistic skills. [...] His self-esteem's just so raised. [...]. He's found his platform to show his artistic ability and everybody looks to him [...] whenever we start talking about anything artistic. [...] They all look to John, you're the artist! [...] What do you think, and can you give us some ideas? And he's loving it.

John described some of the art techniques that he learnt from working with David. In particular, he learnt how to transform 2D drawings into 3D pieces of work. The project allowed John to expand his portfolio, and supported his college studies and aspiration to work in a creative role.

Laila's confidence also clearly grew during the project, and as a consequence she started to think about whether she wanted to be a youth worker, and asked to be put forward for a basic youth work qualification. In her interview, Margaret indicated how the project had influenced the process: 'When she first came to [the] forum she wouldn't have done that at all, no way.[...] I think it's had a major influence on her, because I think Laila's one of those that's took a lot of responsibility'. Laila readily took on the responsibility for actions that came out of the sessions. Through working on the project she gained a greater sense of her capabilities, leading to thoughts of a future career in youth work.

The final Pioneer whose horizons were clearly widened by their involvement with the project was Kerry. As previously described, at the start of the project Kerry was uncomfortable sitting with the group. She appeared anxious with her peers and did not have a sense of her abilities. Through taking on the role as the group's secretary, which involved writing up the minutes, organising the meeting dates via email and photographing/recording activities such as the access audits, Kerry began to grow in confidence. During the project she began to aspire to a career working in an administrative role in an office. Pam reflected on how the project enabled Kerry to think about how she might be comfortable working in a team based office setting:

Kerry has grown so much simply because she's taken on that new role in the group [...] she goes into the office now and helps Andrea<sup>30</sup> [...] [a] couple of days a week doing book keeping and typing [...] She's found this new skill of admin. [...] She loves it. Yeah and we're encouraging that [...] She's really found her role [...] and she is getting more involved because of that, the confidence to get involved. [...] Finding her niche in the group now because before she was just a blank, as you know she would just sit there, no contact, no engagement. [...] she didn't have a place [as] she didn't belong. Now she's like [a] secretary. [...] For me she is the one who's grown the most.

Finding a niche and a role in the group, becoming more comfortable with her peers and learning to be a valuable member of the team were large steps for Kerry. In her interview, Margaret indicated that this new career aspiration was a direct outcome of the project. These examples show how individual Pioneers benefited in different ways through their engagement with the project, and how these benefits opened up new possibilities beyond the scope of the project.

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<sup>30</sup> Andrea is a member of the DST.

### ***Increased Sense of Self-esteem and Pride***

As a consequence of seeing the implementation of their suggestions, the Pioneers gained a great sense of achievement and pride in witnessing the outcomes of their advocacy. As previously discussed Michael expressed shock that the group had been listened to and that changes had happened so quickly in response to their suggestions. All the Pioneers interviewed expressed a sense of pride in attending the opening event and seeing their suggestions unveiled. Their status as the only non-Jewish group to be invited to the launch gave them a sense of their importance to the Centre as partners. When asked about the opening, Katie commented on this directly in her interview: 'I am really proud that we've actually been involved and had the status given'. In her interview, Audrey explained how this sense of pride in their achievements had a positive effect on their self-esteem. Both Audrey and Margaret talked about the pride and confidence that the Pioneers gained through their involvement, and Audrey's comments indicate that a consequence of their achievements was that they challenged the ways that other people viewed them.

### ***Making a Difference: Increased Sense of Personal Agency***

Part of the Pioneers' sense of pride came from their perception that they had made a difference for others. As John explained 'I like helping people [...] that's mainly why I like coming here'. In their interviews, the Pioneers strongly expressed the view that the Centre had improved due to their input, and whilst it was not totally accessible at the end of the process, it had made large steps towards attaining this goal. Laila expressed this sense of achievement in her interview: 'I feel quite good actually, that we actually changed what was going to

be there'. Through their interviews, the Pioneers also expressed the view that they had not only improved access for themselves and other disabled young people that they knew, but also for the wider disability community. Margaret reflected on how this sense of making a difference had impacted the Pioneers' perceptions about what they can achieve:

Well I think what they feel... very, very strongly is that we've made a difference. [...] For a start, we've made a difference to other people that are likely to visit the Centre, and I think for them to feel they've actually contributed to that is a very positive thing. I feel a lot of them have got a lot more confident and self-assured about their ability to express their opinions and will probably challenge other people, and I've seen some of them do that in other arenas.

The ability to question others and advocate for their views gave the Pioneers a greater sense of their own agency. In her interview, Margaret also explained why the opportunity to get involved in a project and make a difference was so important to the Pioneers. She talked about how Kerry was able to help John write down his ideas in a planning meeting, as John finds it difficult to write:

[S]he knew that she could help John. [...] So she was offering some support to somebody else. [...] So she recognises that skill now, and is able to say do you want me to help you? Now, for a lot of the young people we're working with, being able to offer help to somebody else has probably not been ever part of their life. Because most disabled people... what they experience is other people doing to them and for them, but never saying can you give me something back. [...] For most of those young people through their lives it would have been, oh you can't write, you can't read, oh you won't be able to walk that far, oh you can't sit in the group [...] so it's all what you can't do. Nobody very often stops and says [...] we know you can do that are you going to give it a go? And okay if it doesn't work first time then we'll try something else, and it's a process all the time, a process of building their confidence to say 'yes you can' instead. So they now hopefully would start saying, instead of saying 'I can't read' say [...] 'I'm asking you for support to do that'.

As Margaret explained, as disabled children grow up they internalise messages about their limitations and inabilities, which is in alignment with Reeve's (2002;

2004) discussions about internalised oppression in the context of disability. It is clear that the development of the Pioneers' self-esteem and the opportunity for the young people to demonstrate that they have valid skills, abilities and talents to offer others was important. Barnes (1992b) and Swain and French (2000) discuss how disability is often perceived in a negative way, and that it is rare for people to talk about disabled people's abilities. Swain and French (2000), through their development of the affirmation model of disability, place an emphasis on celebrating disabled people's abilities and achievements. This project clearly demonstrated to the Pioneers that if they make a contribution, their knowledge, skills and abilities are valuable to other people, organisations and to wider society. These changes can be very empowering for young people who are used to their lives being framed by negative perspectives.

Before entering into a discussion about the range of ways that the Pioneers were empowered by their involvement in the research, it is important to outline the influence and impact that they had on the Centre staff and the organisation, so that issues relating to their empowerment can be viewed from different perspectives. However, before moving onto the Centre, I will first look at the impact of the research on the youth workers.

## **Impact on the Youth Workers**

The youth workers who supported the project had a wealth of experience in supporting young disabled people through a variety of projects and settings, and did not report developments in their working practices in their interviews. The skills and techniques they used to support the Pioneers to empower themselves and find a voice were ones that they had a lot of experience in delivering. The

main issue identified was how the project had affected them on a personal level. Pam and Audrey indicated that they had learnt a lot about the disability history of the Holocaust, and Audrey discussed how the experience of meeting Holocaust survivors and hearing their stories touched her. For all the youth workers, the research had deepened their understanding about issues of prejudice and exclusion and their links with disability history.

As discussed in the Chapter 4, Margaret Clement was involved in the analysis of the data at three stages, to ensure that I remained accountable to the group and did not misrepresented their views, on reading the final thesis Margaret offered these comments:

I have enjoyed reading this thesis as it has enabled me to reflect on the time we spent as a team supporting this research at The Holocaust Centre. Reflection and empowerment of young people are at the heart of youth work, so being part of this research has given me an insight into different opportunities that this work has presented to our team. The commitment and challenges that presented themselves to all of us during this research have been a learning experience for staff and young people. The outcomes for young people are measurable, [as] individuals have achieved far more than they believed would have been possible. These young people came to this project under-confident and not knowing a lot about disabled people [and] the Holocaust. Using the subject matter enabled us to look at the social model of disability, whilst empowering young people to believe they could achieve. The researcher was patient and willing to work with the young people at their pace which was very important, and is often not the experience of working with partners on these kinds of projects. I believe the young people did make a difference within The Holocaust Centre.

Although Margaret read the whole thesis, there were no elements that she requested to be changed, even though I had indicated that I was open to her critique of my analysis. Her comments were reflective, and supported the analysis that has been presented in the thesis.

## **Impact on The Holocaust Centre and Staff**

The above analysis has demonstrated that the action research had a variety of meaningful outcomes for the Pioneers. However, how did the impact of their work affect the Centre staff? Were the staff influenced by the Pioneers and were their working practices challenged? This section explores what factors affected whether the staff working practices changed. At the start of the research I identified that there was a fundamental split between the way that the organisation perceived its role in society and its daily operational practices. When reflecting on the purpose of the Centre, the staff were unanimous in their view that it played an important role in society. In his interview, James Smith described how the role of the Centre focuses on visitors learning lessons about exclusion, as societies where groups are marginalised and excluded are not cohesive. He commented that if these issues are not challenged they can escalate and lead to hate crimes and violence:

[A] lot of this emerged post Second World War, post Holocaust and what we're trying to do is bring a stark lesson [...] to inspire people that diversity, dealing with hate crime, dealing with extremism is important. Why? Because we've all got to take responsibility.

This issue of responsibility and the implications of overlooking exclusion are interesting when you turn the lens around and, rather than look at society's responsibilities, you focus in on the Centre's responsibilities. Senior management at the Centre identified that they needed to improve access, as demonstrated through the creation of an Access Officer role. However, as discussed in Chapter 4, initially it was not clear that this role would involve working with the whole staff team, or that it would go beyond physical access improvements. Due to the methodological issues related to my role at the

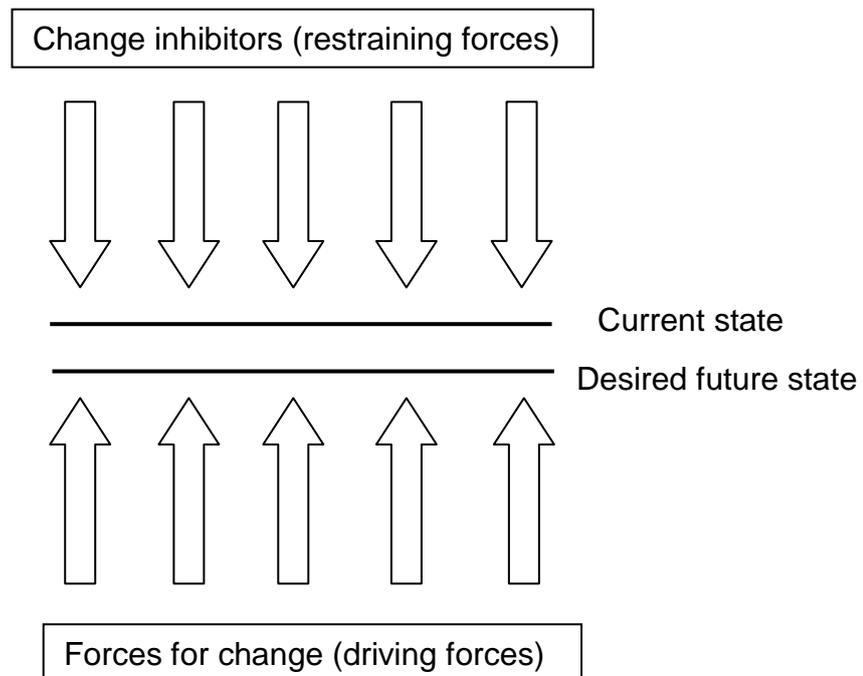
Centre, I was not able to track developments in the working practices of the staff. However, I was able to analyse staff perceptions of changes to the Centre through their interviews. It was interesting that I was not able to find an approach within the museum literature that specifically gave guidance on the processes of organisational change in supporting a museum to become more inclusive. The museum literature calls for museums to move work with marginalised communities from the periphery to the core of organisational priorities (Black 2006; Lynch 2011b; Nightingale and Mahal 2012), but does not offer detailed guidance on what museums need to do to make these changes. Therefore, a broader reading of literature from allied fields is required to support an understanding of the issues that arose from the analysis of the data in relation to the process of change at the Centre.

From within the field of management studies Wilson and Rosenfeld (1990) and Senior and Fleming (2006) identify factors that affect an organisation's capacity to change, but the management studies literature does not focus on issues relating to excluded communities (it tends to focus on corporate rather than non-profit organisations). The most useful model for thinking about organisational change is put forward by Lewin (1951), with Sandell (2003) discussing the seminal nature of Lewin's work and its relevance to the museum context.

Sandell (2003, 49) explains: 'the overarching concepts he developed to explain individual behaviour, resistance to change and group dynamics have been widely adapted by management theorists to explore organizational change in the last five decades'. Sandell also examines how Lewin's (1951) 'Force Field Analysis' is widely used within the organisational change literature, and states that it can be applied to the museum context to identify and explain why

museums can be resistant to engaging with social inclusion agendas. His application of Lewin's work focuses on the factors involved in whether the museum sector is able to respond to the social inclusion agenda.

Cameron and Green (2007, 96) cite Lewin (1951) in explaining that his approach 'examines the driving and resisting forces in any change situation. The underlying principle is that driving forces must outweigh resisting forces in any situation if change is to happen' (see Figure 46). Focusing on the issues that arose from my observations working with the staff, and my analysis of their interviews (when situated alongside the work of the Pioneers) allowed an understanding of the change inhibitors and the forces for change that affected the ability of the Centre to move from an organisation that was committed in principle, to inclusion, to one that was actively working towards becoming a more equitable and inclusive place (see Figure 47).



**Figure 46: 'Force Field Analysis' (after Lewin 1951)**

### ***Organisational Issues at the Start of the Fieldwork***

Figure 47 allows a complex analysis of the factors that were in play at the Centre and when looking at this figure, it is interesting that many of the issues that arose from an analysis of the data were identified within the museum literature. For example, Fleming (2002; 2012), Lang (2006), Janes (2009) and Nightingale and Mahal (2012) identify the importance of strong leadership to drive through change in the area of equality, Smith, Ginley and Goodwin (2012) focus on the need to support disabled people to share in decision-making. However, the series of issues highlighted in Figure 47 are often discussed in isolation in the literature, and this is the first time they have been drawn together and linked with the processes of organisational change that can occur when museums aim to tackle exclusionary practices. My analysis draws on Lewin (1951) as it focuses on the issues that were inhibiting change at the Centre, and the factors that were driving or supporting change. The arrows in the figure show the interconnected nature of the highlighted issues, and the central line represents how museum practice can be seen to be on a continuum in relation to the degree to which museums are inclusive and equitable places.

Figure 47 represents the position of the Centre at the beginning of the period of fieldwork (January 2007), and Figure 48 represents the position of the organisation at the end of the fieldwork (October 2008). In both figures, the green colour-coding represents elements that the Centre had implemented. Orange represents those that the Centre had started to work on but had not fully implemented, and red represents issues that still needed to be addressed. At the start of the fieldwork it can be seen that there were more factors inhibiting than supporting change. Senior management was yet to fully understand its

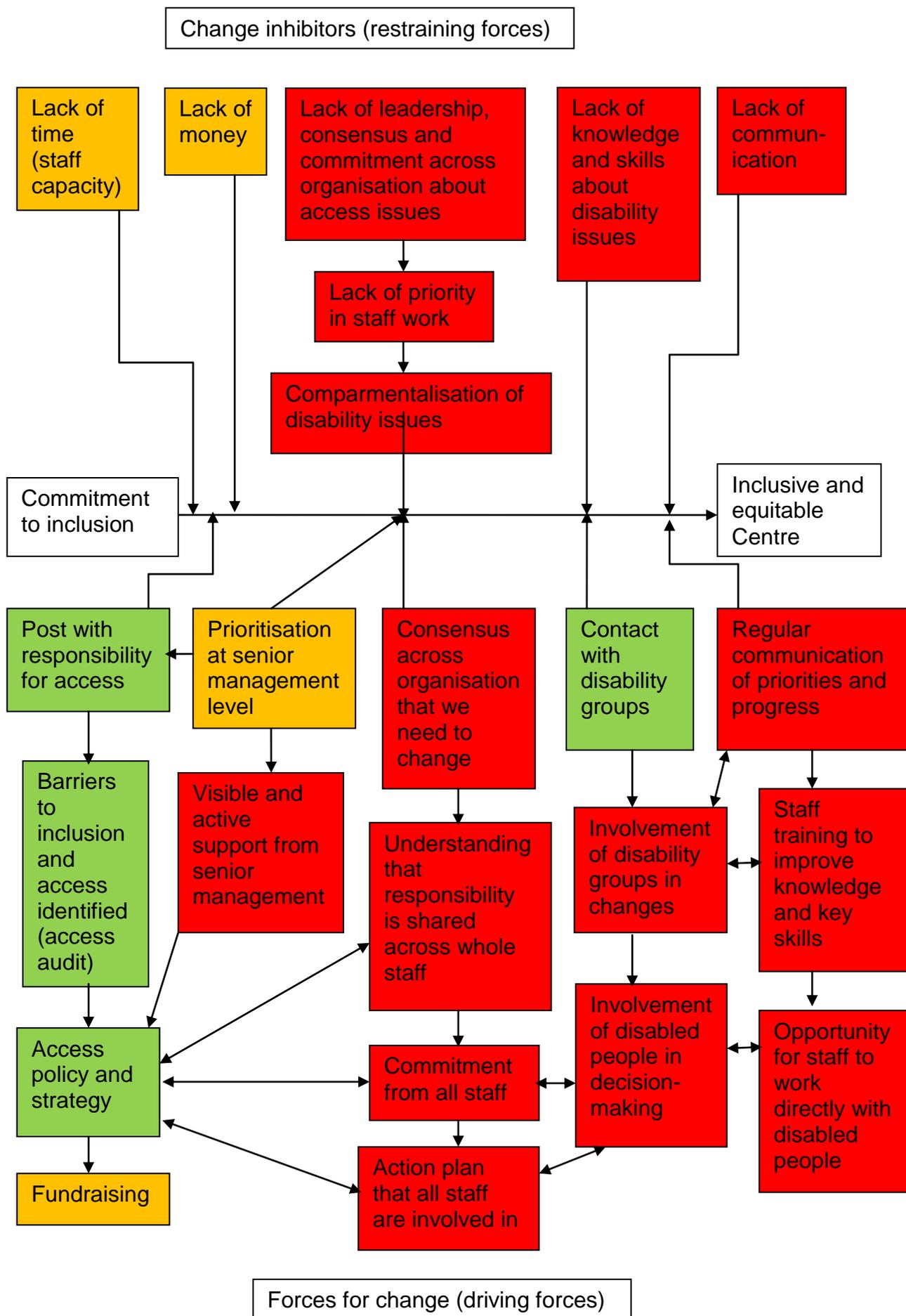


Figure 47: Analysis of the change inhibitors and forces for change at the start of the fieldwork

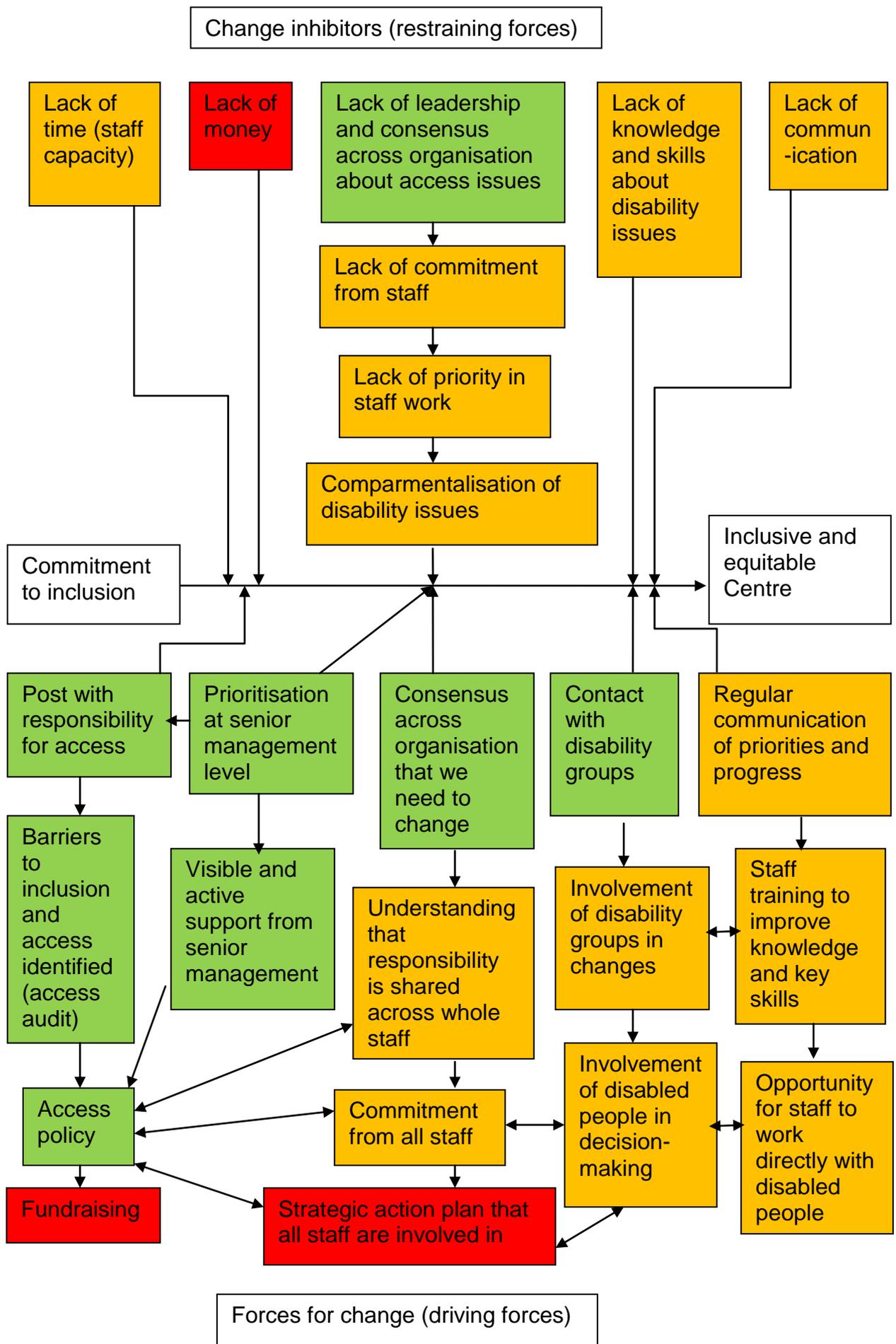


Figure 48: Analysis of the change inhibitors and forces for change at the end of fieldwork

leadership role with respect to equality issues; there was also a lack of consensus across the organisation that everyone had a responsibility to prioritise equality issues, which led to disability issues being compartmentalised within the Access Officer role. Funding had been raised through the Heritage Lottery grant for *The Journey* exhibition, which would enable some inaccessible features of the site to be addressed. However, staff across the organisation lacked skills in this area, and there were no mechanisms in place at the Centre to communicate priorities to the whole staff, as staff did not work from policy documents, and there were no staff meetings or appraisals in place where priorities were discussed. However, in my access role I had identified barriers to access on the site (Hollins 2005), created an action plan and contacted local disability groups. I had also started to work with senior management to improve their understanding of the issues on-site. Initially however, the responsibility for improvement in equalities issues was dependant on the changes that I undertook initially, from the periphery of the organisation.

### ***Organisational Changes at the End of the Fieldwork***

From an analysis of the interview data and the visible changes that had occurred on-site, understanding how the organisation had changed could be assessed in comparison to staff reflections about the early stages of the research. By the end of the fieldwork, the issues that were contributing to, or driving change, could be grouped under the headings of: senior management leadership, the influence of strategy and fundraising issues, the Centre staff having a shared understanding of and responsibility for equalities work, and the influence that disabled people were able to exert on the organisation. When viewing Figure 48,

the combination of these issues demonstrates that the Centre had moved forward in its approach, and that the drivers for change were now stronger than the inhibitors. However, as will be seen later on, there were significant inhibitors which could prevent change in the future, and by the end of the fieldwork the organisation could not be described as a fully inclusive and equitable place.

The next sections will look at the broad headings of senior management leadership, the influence of strategy and funding issues, staff responsibility for equalities work and the influence of disabled people on the organisation, in order to consider the process of organisational change that occurred.

### ***Senior Management Leadership***

Fleming (2002; 2012), Lang (2006), Janes (2009) and Nightingale and Mahal (2012) discuss the importance of strong leadership to drive through change in the area of equalities. In their interviews, both James and Stephen Smith identified that it was important for senior management to take a strong leadership role to ensure that staff prioritised equalities issues. Stephen Smith discussed the importance of his intervention in the car park development plans when another manager was championing an inaccessible design. He saw this as a turning point in his thinking, and the start of him taking a more active and visible role in supporting disability access. This change is seen as central to the improvements at the Centre.

### ***Influence of Strategy and Funding***

This is the only area that moved in retrograde by the end of the fieldwork. At the start of the process a clear strategy was developed that highlighted key issues

to be addressed in the refurbishment and development of the new exhibition. It also highlighted more long-term access improvements needed in the site and its facilities and programmes. However, at the project's completion the organisation had just launched the redevelopment and *The Journey* exhibition, and there was a need to re-evaluate organisational priorities post-launch. However, the Centre was not the type of organisation that highly regarded the role of strategic planning as an approach to communicating staff priorities. In the management studies literature, Morgan (1989) comprehensively describes the differing ways that organisations can be structured providing examples of hierarchical and bureaucratic structures along with more informal structures focused on tasks or project management. In their interviews, James and Stephen Smith described the staffing structure as being non-hierarchical, as most staff reported directly to them. Of the types of organisational structures described in the literature, the Centre most closely resembles the characteristics of an 'adhocracy.' Drawing on Mintzberg (1983), Senior and Fleming (2006, 99) describe an adhocracy as an ad hoc group of professional people 'who are brought together for a single purpose associated with a particular project'. Normally, this organisational structure is disbanded after a project is completed. However, in the case of the Centre I would argue that it is the standard working structure for the organisation. This structure is characterised by 'having few formal rules and regulations or standardized routines' (Senior and Fleming 2006, 99). Drawing on Pugh et al. (1969), Senior and Fleming (2006, 99) state that 'adhocratic' organisations are 'flat, but with horizontal differentiation generally high as adhocracies are staffed mainly by professionals, each with his/her own specialism'. This is borne out by the Centre's staffing structure which is a flat

structure with few tiers of management.<sup>31</sup> As it has a small staff teams, specialisms were often covered by one post holder, which would have been fulfilled by a team of people in larger museums.

The effect of this type of staffing structure and organisational culture is that strategic planning, particularly in written formal documents, is not a strong part of the culture. This type of structure poses additional challenges as it is not natural for the whole organisation to conform to a specific strategy or way of working, and post-launch there was no strategy in place to take the organisation forward.<sup>32</sup> Also, once *The Journey* exhibition project had been completed, the major source of funding available for access improvements had already been utilised. Funding to support future changes would need to be raised to enable further access improvements. Indeed, 11 staff pinpointed the need to raise funding, or cited the lack of funding as a future issue that would prevent change. However, it was encouraging that in their interviews, fundraising staff now saw disability access as an issue to include in future bids.

### ***Shared Understanding of and Responsibility for Disability Access***

When looking at how staff responded to whether they believed that disability access was a priority in their work, a number of factors can be identified. An important factor was that staff needed to have good knowledge and skills in relation to disability issues in order to implement them in their work. During the action research, 15 staff attended disability awareness training (delivered by a

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<sup>31</sup> As staff below Chief Executive level did not consent for their names or job titles to appear in the thesis, this meant that it was difficult to include a diagram of the staffing structure. Details of the staff roles across the organisation are found in Appendix 1.

<sup>32</sup> *The Journey* Business Plan 2005-2010 (THC 2005b) only focused on issues relating to the development of the new exhibition.

disabled person), and 17 out of 20 staff either directly met the Pioneers or worked alongside them on the event to remember the disabled people who were killed in the Holocaust. 15 members of staff were able to talk about the changes they had made to their working practices in response to the training, working with the Pioneers or responding to my influence as Access Officer. For example, a member the maintenance staff discussed how he now thought about these issues in his work:

If I'm doing anything, I always think about if somebody disabled came along... if the path, it have got roses coming to edges then I think would them roses be in way if I were on a chair? It wouldn't scratch me face or... Another thing is bird droppings and floods [on the paths]. I have to get rid of them in the morning [...] you know, for people with sticks or who can't see.

This illustrates how this staff member had thought about people with different impairments and how this issue related to their daily work. The range of responses came from administrative staff (who now thought how they can support people with impairments at events), marketing and design staff (who now considered access issues in marketing materials) and education staff (who factored in inclusion when delivering learning sessions). The data demonstrated that the majority of staff now considered disabled people's needs as part of their work. This was in direct contrast to the start of the research, when staff deferred responsibility to my role as Access Officer. However, the extent to which they prioritised disabled people in their work was not clear from the data, and further investigation would be needed to more fully establish this issue.

11 members of staff were able to talk about the influence of the Pioneers on the Centre. However, the depth of staff understanding about their input was dependant on whether they had directly worked on the refurbishment and *The*

*Journey* exhibition. For example, the Chief Executives and *The Journey* team were able to talk in detail about how they valued their input:

Staff member: They've given the senior management a thorough grilling! They've been invaluable in helping the Centre improve its accessibility for the disabled people. I think it's terrific that we were able to have their input.

Stephen Smith: I think it has been important for the Pioneers to be seen to be a part of a process of developing this Centre, and to know that those voices are going to be incorporated into our thinking and converting that into practice has been important. It's been exciting to see how simple it is to make our resources accessible to everybody. How simple it is not to build barriers in to everything that you do, just by not thinking.

It is clear from staff who had worked directly with the Pioneers, or who had been involved in my mediations of their input, that the Pioneer had exerted a considerable effect on their thinking. However, staff who had not been involved in the redevelopment, who were new to the organisation or who worked in administration/finance roles 'behind the scenes' had little or no understanding of the Pioneers' work, and in some cases could not identify the changes that had occurred on site:

Well, all I know is that you have brought groups in and that the whole idea was that these people by being users would inform us about what we could actually do and achieve. So presumably you've got a long list of things that these people must be saying. And presumably nothing's been done about them, unless you've incorporated things into *The Journey*?

This staff member showed little awareness of the work that the Pioneers had undertaken, and how it had had an influence on the Centre. Overall, six members of staff had no awareness of the Pioneers' input, and a further five members of staff only had a basic awareness of work that they had undertaken. Three members of staff had limited awareness of the changes to the Centre, and one member of staff could not identify any improvements. However, this

member of staff had only been working for the Centre for less than two months and, therefore, had arrived as the refurbishment was launched. Five staff members were also not able to talk about changes to their working practices; this correlates to the experiences of the staff who were not part of *The Journey* team.

However, it is interesting to note that despite some staff's low awareness of the specifics of the Pioneers' work and the changes on-site, the majority of the staff (15 members) reported examples of how they had changed their working practices in response to the need to think about the needs of people with impairments, and 11 staff reported on ways that the Pioneers had had an influence on their work. From their interviews, a range of factors were seen influencing this overall picture, which included disability awareness training, the work on the disability history event, my role as Access Officer and the opportunity to meet/work with the Pioneers. Drawing on Nadler (1993), Sandell (2003, 50) states that when managing organisational change within museums there is a need for 'an holistic approach with multiple and complementary strategies that together can support and encourage sustainable developments'. Therefore, although the Pioneers had an influence on the Centre, there was a need for other strategies to be implemented alongside their work to support organisational change, as it was not realistic that a single strategy would influence all staff.

Overall, this analysis has shown that, although there was support from senior management and a consensus across the organisation that disability issues were important, as can be seen in Figure 48, at the end of the fieldwork not all staff were actively implementing it in their work, and the

understanding/prioritisation of disability issues was not uniform across the organisation. However, Figure 48 illustrates that the organisation made significant steps forward to become a more inclusive and equitable organisation, and that more work was needed to fully embed these issues.

In terms of factors that were inhibiting further change, 18 staff members identified specific issues: 11 staff pinpointed the need to raise funding or the lack of funding as a barrier, three members of staff referenced staff capacity as an issue, three members of staff claimed that some staff were not prioritising access issues as part of their role, and one member of staff named the competing range of priorities as a problem. This indicates that there were still forces acting against future changes, and that funding was considered to be the most significant issue.

In terms of the organisation not being able to transform itself to become totally inclusive and equitable, I would argue that this process would take longer than the one year, ten month period of the fieldwork, particularly given the position from which it started. As stated by Elliott-Kemp (1982, 6), 'anyone seeking to effect significant change in an organisation will have to take account of the potential effects of customs, myths, norms and values on the way the change is perceived within the organisation'. Therefore, influencing and changing whole organisational practices in a complex area like equalities issues across a long-term process cannot be achieved through a single project.

As discussed by Elliott-Kemp (1982), there is a need for a person in the role of a 'skilled change agent', who leads the process of change and influences other staff. Elliott-Kemp asserts that a change agent needs to have the power and be

in a position to drive, enact or influence change. The Pioneers can be seen as change agents, as they influenced the organisation and gained the expertise and social capital to support the change process. In a workplace context, Cameron and Green (2007) define a change agent as a person who takes on the roles of a data gatherer, educator, advisor, meeting facilitator and coach. 'Most often he or she has no direct line authority over the implementers' (Cameron and Green 2007, 138). In this context, I can be seen to have acted in the role of a change agent as I influenced senior management and staff across the organisation. In the staff interviews, both Chief Executives indicated that an Access Officer had been central to this process, and nine members of staff highlighted it as a key issue. For example, a member of *The Journey* team stated:

Heather: What things have supported the changes?

Staff member: I would say mainly because you've been here. That's the only reason why things have changed I think. [...] Because you've been here and you've been focused on it, and you've stood up for these things to happen, which has never happened before.

As previously discussed, although senior management leadership has been identified as a key factor in influencing change, as cited by Cameron and Green (2007), Senge et al. (1999) argue that there is a need for leadership and support regarding issues at different levels to enable changes to be implemented. Green (2007) builds on this idea of influences at different levels to identify six types of positions that people hold when engaging with change: blockers, sponsors, champions, preachers, sleepers and willing workers. He identifies them in terms of their power over and commitment to change. Following this approach:

- **Blockers** are people who obstruct change and have a high degree of power and low commitment to change.
- **Sponsors** are highly committed to change and are in a position of power to enable it to happen.
- **Champions** have a high commitment to change and may be active advocates and implementers of change. They may be visible leaders or have a specific role in the change process and will influence others. Elliot-Kemp (1982) describes these people as change agents.
- **Preachers** are vocal in their negative perceptions about change and have low commitment.
- **Willing workers** are committed to implementing change but are not in positions of power.
- **Sleepers** are people who cannot be bothered about change, as they are not interested in it or are not aware of it happening as they have not been invited to be involved.

In this approach, Green (2007) considers how power, commitment and motivation affect how staff engage in organisational change. However, there is one additional factor that he has not considered in relation to the specialist knowledge and skills that are needed to make appropriate decisions and, therefore, successfully implement actions. When taking this additional factor into account in relation to the need to improve disability access the following picture can be built up of the staff at the Centre:

1. **Access blockers:** At the point that the staff were reflecting on the changes that had happened during the redevelopment, none of them fell into this category. Initially, however, there were staff who fitted this description. These staff did not have an understanding of the range of access barriers on-site, and did not see why it should be part of their role. They were in a position to block change due to the power that they held over budgets and/or staffing issues. In the context of disability access these staff members were initially

only interested in complying with minimal actions to avoid prosecution under the DDA (1995).

2. **Access sponsors:** These staff members were committed to improving access, were in a position of power, were motivated to see change and had enough knowledge to make appropriate decisions or consult with people with the knowledge to support them with decisions (the Access champion and/or external access groups). At the Centre this described the Chief Executives and the project manager of the refurbishment.
3. **Access champions:** These were staff who were committed to improving access, and who had an excellent understanding of the access barriers and solutions. It was a central part of their role to drive change and influence other staff. They had built up specialist knowledge about access issues, and were in a position to share this expertise with other staff. In their role as advocates they supported external organisations to have an influence on the organisation. This described my role as Access Officer, and James Smith detailed my role further:

I think our understanding of the breadth and the complexities of access, not just at a senior level, but throughout the organisation has improved. Everything from design to media, people talk about it, it's partly because of your presence there. If you were [...] an outside consultant that came and talked to people every now and then, I don't think it would make a change. [...] But the fact that you're here, you're an integral part of the development and design team means that other people on that team have learnt from you. [...] in your absence, for example, I often hear reference to you [...] somebody will say, 'I think Heather will have a comment about that [type] font'. [...] Now the fact they're saying Heather will have a view about it means that they know that it's not right and, therefore, why don't we change it before Heather points it out.

This passage illustrates that I had shared my knowledge of accessible design with other staff, who had initially treated me like the 'Access Police'. Due to a growing commitment to access, staff members considered these issues and sought my guidance. It also points to the importance of having a person on the staff responsible for equalities issues. This is in agreement with Nightingale and Mahal (2012) and Smith, Ginley and Goodwin (2012).

This passage also illustrates that in my physical absence from rooms, my presence on the staff meant that I acted as an 'equalities conscience' and a point of accountability for the organisation.

4. **Access implementers:** These 'willing workers' were staff members who understood the need to improve access, were able to diagnose some access barriers and were able to articulate how they related to their role. They were committed to improving access, but did not always have the specialist knowledge to implement accessible actions. This meant that these staff members sometimes made unintentionally inaccessible decisions. However, they were willing to learn more and were supportive of change. It is interesting to note that the majority of staff fell into this category.
5. **Access followers:** These were staff members who had an understanding of the need to improve access issues, but who did not always see it as important. They did not necessarily see how issues of access applied to their role, and therefore did not take ownership of making accessible decisions. They were also not always open to learning more about the issues as they were not necessarily motivated to change. This meant that they needed to be persuaded to work in an accessible way, or needed to be directed by the Access sponsor to accept changes to their working practices. A member of the design team fell into this category. When asked about what further training they would like, one responded:

I don't feel as though [it will] benefit me that much. I think I probably just need to be a bit stricter with myself. [...] Most of the time I know what's needed from an access point of view on design, I know what's needed, but it's making myself do it all the time.

This member of staff often needed persuading to change their approach through the Access champion's influence or the Access sponsor's direction.

6. **Access deniers:** These staff members thought that they understood access barriers and access issues and therefore did not need to listen to advice on how to change their working practices. They indicated that they were committed to access and that they had a basic level of knowledge. However,

they did not prioritise access issues within their work and did not see that they were working in an inaccessible way. They were not open to their practices being challenged and in some cases were dismissive about the need for change. They did not take responsibility for making changes in areas that they had influence over. These staff are the most difficult to work with, as they can often think they are already access 'experts', which meant they were be poor listeners, as they did not think the discussion applied to them. It was interesting that the members of staff in this category were experienced educationalists who had worked with 'special-needs' pupils in the past. Their interviews indicated that they focused on the problems rather than the solutions:

I think it's a very, very low priority. [...] I think the physical access is dreadful, absolutely dreadful. [...] I mean, it must be a lower priority than even heating in the hall, I would suggest, because nothing is ever done about it, in spite of me almost daily pointing it out. Because every time we have schools and groups and there are people with disabilities in chairs etcetera we have a problem.

This member of staff did not take ownership of the issues that they actually had control over and could change, choosing to defer responsibility to others. This is similar to Green's (2007) 'preachers' but there is an additional failure to understand their lack of skills, which makes this category different.

7. **Access sleepers:** These were staff members who were not aware that there were access barriers on-site, had little knowledge of disability issues and had not considered these issues as part of their role. This only applied to one member of the administrative staff, who was the newest member of the organisation and who had low awareness of disability issues from their previous life experiences.

Additional categories – 'followers' and 'deniers' – can therefore be added to Green's (2007) approach when considering staff knowledge and skills. This analysis supports a greater understanding of the issues that underscored different staff members approach to issues of equality. In the next section, this

analysis will become important when analysing why inaccessible decisions were made as part of the refurbishment.

### ***The Influence of the Pioneers on the Centre***

The influence that the Pioneers had on the Centre can be analysed from three perspectives. First, there was the influence that the Pioneers and the youth workers felt they had on the Centre and its staff, as revealed by their interviews; second, there was the influence that the Centre staff indicated the Pioneers had on the Centre in their interviews; third, there were the visible changes that occurred to the site, and the question whether the Pioneers had indeed had an input into them (assessed through the Pioneer session content in comparison to the photographic records taken of the site).

### ***Impact on The Holocaust Centre Site, Facilities, Exhibitions and Programmes***

*The Journey* exhibition aims to take children on a narrative journey to explore how Jewish children were affected by the prejudices of the Nazi regime. On arrival, an introductory area with a piece of film introduces pupils to the concepts of enjoyable journeys and the need for some children to go on journeys to flee from danger, introducing refugee children's experiences. A lift then 'transports' the children back in time to 1930s Germany, and they 'arrive' in a typical Jewish-German dining room, complete with a table laid for the Shabbat with chicken soup and bread on the table (the room smells of soup). Also, in the room are a writing table, wardrobe, sideboard and toy box all of which can be explored. A TV screen plays a video introducing a fictional child named 'Leo Stein'. The

pupils follow his story through each of *The Journey's* rooms to explore how the rising anti-Semitism affected children. Figures 49 and 50 show the immersive environment. There are no 'traditional' museum panels or labels in the room.

The school sessions are led by one of the Centre's education staff, and activities in each room are designed to uncover the story and the meaning of the objects.

For example, in the toy box (Figure 51) has a glass museum-grade case housing real 1930s toys (loaned or donated by Holocaust survivors) built into it with 1930s toys (with no specific provenance) on top for children to investigate.

An investigation of the room enables the uncovering of stories about these objects and the touch screens trigger short pieces of film, with survivors talking about their childhood memories of friends, toys and the rising anti-Semitism that they started to encounter (Figure 52). This creates an experiential learning experience that enables a multi-sensory, hands-on approach (i.e. items to investigate, film to watch, sounds of the street to listen to and food to smell). All the real and replica objects in the room are situated in context. This approach is then carried on throughout the other room settings taking the pupils on a journey through anti-Semitism in the classroom (Figure 53), rising violence in the streets and the decisions that families needed to make about whether to go into hiding (Figure 54), escape or 'wait it out', which inevitably meant that families went on journeys to ghettos or to death camps. Some parents were able to send their children to the UK on the *Kindertransport*.<sup>33</sup> Each of these decisions are explored in a room setting. The exhibition, however, does not explore the experiences and deaths of children in the ghettos and camps, as psychologically

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<sup>33</sup> The *Kindertransport* took place during the nine months prior to the outbreak of the Second World War. Nearly 10,000 (predominantly Jewish) children, mainly from Germany, were placed with UK families and were often the only members of their families who survived the Holocaust.



**Figure 49: 1930s Jewish-German home**



**Figure 50: 1930s German home. Details of the table setting with items that can be touched and smelt**



Figure 51: Toy box with toys that can be handled

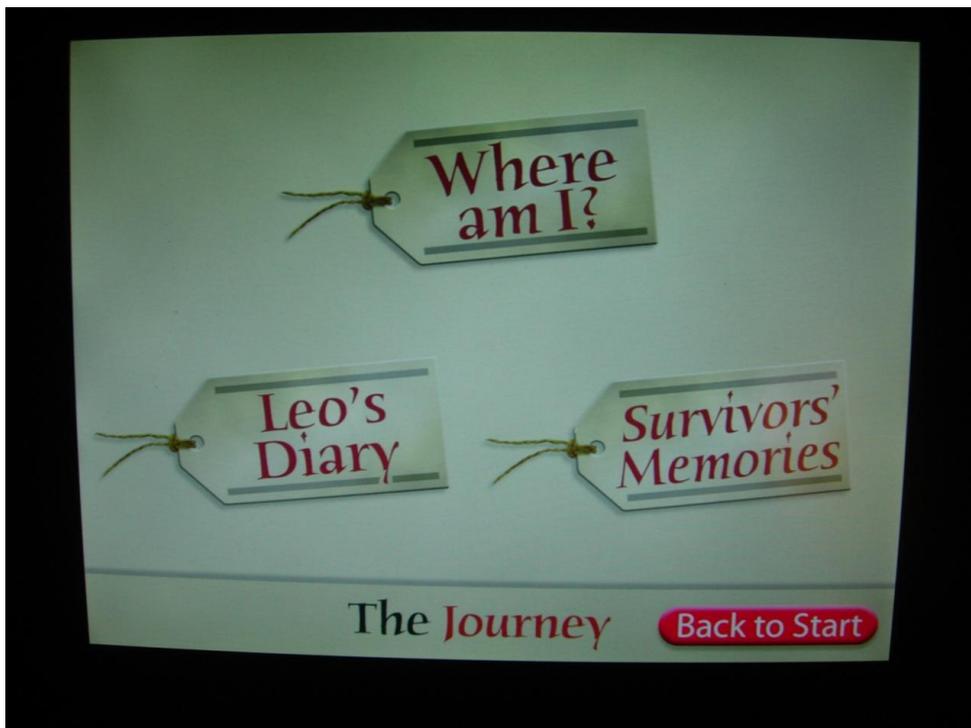


Figure 52: Touch screen that triggers films about Leo's story or survivors' memories



Figure 53: 1930s German classroom



Figure 54: The Stein family's tailor shop (with a concealed hiding space)

primary-aged children are not able to examine such content. Instead the exhibition focuses on issues of prejudice, separation and exclusion.

Holocaust survivors, primary teachers and children and the Pioneers all had an influence on this interpretive approach. Survivors' stories and their personal possessions are embedded into the space, and consultation allowed the survivors to influence how they wanted their stories to be represented. The needs of the national curriculum and teachers were considered, along with the way that primary children learn.

The original design for the space utilised high-tech interpretive techniques to convey the same message. An early visual of the '1930s German home' is seen in Figure 55.

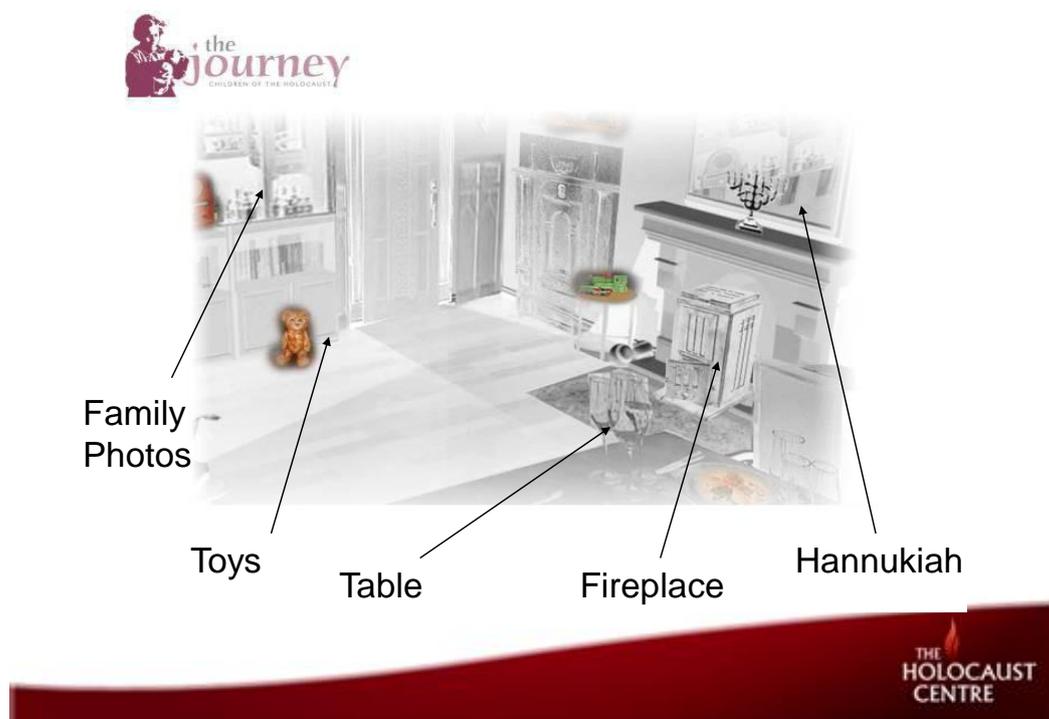


Figure 55: Early design of the 1930s German home. PowerPoint slide from a visual presentation of the exhibition plans (courtesy of The Holocaust Centre)

The initial external designer's idea was to create a blank space in shades of grey, where only the key objects from survivors are highlighted in colour. The walls were to be made from a grey plastic material to simulate wallpaper, and images of survivors' faces as children would appear on the walls, morphing into their elderly adult photographs.

In this draft design, interpretive techniques were at the forefront of the approach rather than the audience's needs. When the Pioneers viewed the designs, they highlighted how the abstract concepts involved in this approach would be difficult for people with learning impairments to fully understand. They also discussed the difficulties that people with visual impairments would have with the space, as the grey shading of the table would blend into the grey walls and floor. This feedback, in conjunction with the feedback from schools, led to the development of the immersive, hands-on and experiential interpretive approach as described above (and seen in figures 49 to 54).

The visit to the Imperial War Museum also enabled the Pioneers to apply an enhanced understanding of interpretive approaches and museum access issues to the new exhibition plans. At the Imperial War Museum the group used the exhibition's audio tour, which is designed to supplement the text in the exhibition for people who find the content hard to read. Feedback from the Pioneers indicated that the headsets had placed them in 'separate bubbles' creating an isolating effect which interfered with group discussions (see Figure 56). They indicated that they wanted to experience the exhibition content as a group, so that they could discuss the experience together. The need to read many labels and panels was also difficult for the Pioneers with Dyslexia or reading difficulties, which paralleled their experience with the Centre's exhibition.



**Figure 56: Imperial War Museum's Holocaust exhibition. The Pioneers are standing in front of a text panel using the audio tour<sup>34</sup>**

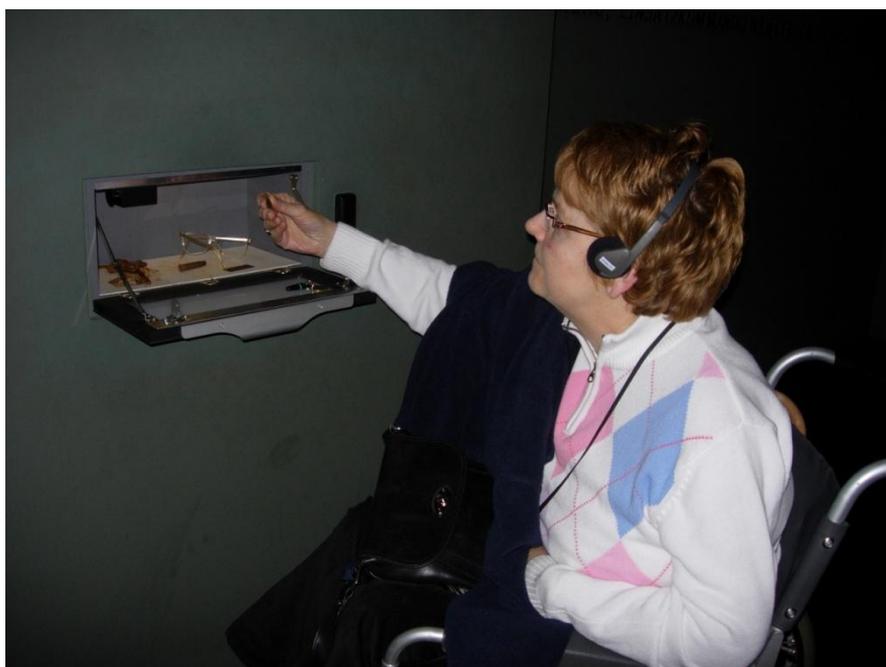
Additionally, both at the Centre and at the Imperial War Museum the Pioneers learnt far more from engaging with the films. Drawing on all of this feedback was instrumental in the interpretation of *The Journey* being led by a film narrative about a fictional child and Holocaust survivors talking about their experiences, supported by a member of the education staff facilitating discussions to enable groups to investigate the exhibition.

At the Imperial War Museum, the Pioneers also benefited from the touch objects that were in special boxes dotted throughout the exhibition (see Figure 57). This feature was part of the museum's access provision, and disabled people could

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<sup>34</sup> The young disabled people seen in this photograph are members of the main Pioneers Forum. They were invited by the members of the Pioneers Holocaust sub-group to join them on the visit to the Imperial War Museum.

book a special magnetic key fob to gain access to the boxes. However, although the Pioneers benefited from the discussions that arose from these touch objects, the Pioneers did not always understand the context of them, as they were linked to text panels. Building on this feedback, *The Journey* exhibition was developed to include real, replica and unprovenanced objects placed in context on open display in the room settings (figures 49, 50 and 51).



**Figure 57: Pam Ellison (youth worker) opening one of the object boxes**

In my role as Access Officer I mediated their feedback and this was fed into the interpretation process. The group was updated on the progress of the plans so that they could critique the proposed accessible interpretive solutions. The overall design focused on creating an holistic interpretive approach that took account of all the stakeholders' needs. This approach was where the Pioneers had the greatest input and influence. The Centre carefully considered their advice and embedded it into their approach. However, when the Pioneers access audited the new redevelopment, they identified existing features of the

Centre that had not been altered, and even drew attention to new features that were inaccessible. It is therefore important to analyse what happened to undermine the accessibility of the approach.

First, some of the issues that the Pioneers identified were outside the remit of the refurbishment. Initially, funding for *The Journey* exhibition was raised through the Heritage Lottery Fund. The full impact of an additional four primary schools visiting the site each day had not fully been considered in the bid. Due to this eventuality, additional funding was raised to upgrade the car park, signage, reception space and café. Additional classrooms and a lunch space were created on the second floor of the building specifically for the primary classes. Major alterations to the layout of the gardens, to the memorial hall and to the doorways in the building were not covered by the additional money that was raised. One of the private donors who supported the redevelopment gave £15,000 to enable a 'cosmetic' upgrade of the main Holocaust exhibition, so that it did not look so 'tired' in comparison to *The Journey*. This allowed broken items to be replaced, upgrades to be made to the audio-visual equipment and quality of the films, and a fresh coat of paint to be applied. As part of this upgrade some of the issues that the Pioneers raised concerns about in their audits were built into the changes. For example, captioning was put onto all the upgraded video so that Deaf people could gain access to the content, and a new floor was laid in the 'ghetto' street scene to replace the very uneven cobbles that were difficult or painful to walk on for people with ambulant physical impairments or arthritis.

However, within the changes in refurbishment and to *The Journey* there were issues that 'slipped through the net'. My observations on the situation were that as the deadline for the launch got closer, the team met less frequently and

formally to discuss plans, decisions and progress. Staff who had not been part of the core team were 'drafted in', and were delegated tasks as the development fell behind schedule. As my access role was part-time, I was not always available to consult on last-minute changes. Furthermore, issues stopped being passed on to me to take to the Pioneers meetings as they met every three weeks, a pace now too slow for some decisions. Therefore, in this fast-paced and multi-staffed approach, the commitment, motivation, knowledge and skills of staff to make accessible decisions became ever more important. Staff who could be categorised as Access implementers, who were committed to access issues, did not always have the knowledge and skills needed to make accessible decisions, and the Access followers and Access deniers did not necessarily prioritise them at all.

Tangible examples of where these factors had an influence are as follows.

Although the Pioneers had an input into captions being incorporated into the upgraded film in the main exhibition, this issue was overlooked by an Access implementer in *The Journey* team who managed the production of the films.

Therefore, none of the film in *The Journey* had captions. Another example was that, in response to consultation with the Pioneers, accessible signage had been installed in the gardens, white lines and handrails had been added to the step to help people with visual impairments navigate the route to the reception (a physically accessible route already existed) and a member of maintenance staff spent a lot of time pruning back the roses and removing slippery moss from all of the pathways in order to make them more accessible for people walking with sticks. However, a member of the administrative/finance team was asked to purchase new benches for the gardens, as the existing ones were in disrepair,

and made their decision about the purchase purely on aesthetic grounds (see Figure 58). These benches were aesthetically pleasing but lacked a back and arms and were uncomfortably uneven to sit on. This decision meant that they were less accessible for people with physical and visual impairments than the benches they replaced.



**Figure 58: Less accessible new bench**

The impact of this on the refurbishment and the new exhibition was that when the Pioneers had input into decisions the features were accessible. However, the Centre was 'peppered' with the consequences of staff's inaccessible decisions, made in isolation without the Pioneers' or my advice. This meant that the overall experience was not fully accessible for people with different impairments. However, at the end of this process the Centre had moved forward considerably in terms of access to the site, facilities and programmes.

Additionally, the representation of disabled people's experiences during the Holocaust had been considered in *The Journey*. Special efforts had been made to make contact with a blind survivor of the Holocaust (there are very few disabled survivors of the Holocaust living in the UK). He was filmed for the exhibition, and his experiences of being blinded by a member of the Hitler Youth and escaping to the UK as a refugee were incorporated into the survivor testimony. Therefore, the influence of the Pioneers was felt not only in the design of the space, but also in terms of representational issues.

### ***The Pioneers' Self-empowerment***

When thinking about what is meant by the term empowerment, it is useful to go back to Solomon (1976), whose work so centrally revolves around this issue. She defines the term by describing it as an active process: 'Empowerment refers to a process whereby persons who belong to a stigmatized social category throughout their lives can be assisted to develop and increase skills in the exercise of interpersonal influence and the performance of valued social roles' (1976, 6). Deconstructing these elements, the Pioneers clearly gained the skills needed to exert a significant influence over the Centre and which enabled them to perform a valuable role, not only on behalf of the young disabled people who they knew, but also in terms of supporting the wider disability community, helping them to gain access the site, its content and the experience. Following a process that was underpinned by the emancipatory principles supported the Pioneers to empower themselves. Through the project they gained the advocacy skills needed to influence others, and developed a greater sense of their own agency. This will be beneficial in future situations where they feel powerless;

and the advocacy skills that they learnt are now clearly being transferred to other areas of their lives.

As Solomon's (1976) definition implies, empowerment creates the opportunity for oppressed peoples to engage in roles where they can exert an influence on the issues that create oppressive practices. In this study, the Pioneers challenged exclusionary practices at the Centre. These actions now have a wider impact on the disability community and the 'expertise' that they demonstrated meant that they became valued partners. Through their partnership work with the Centre, the Pioneers built up the social capital needed to influence change. This concurs with Newman (2006a), who describes how communities can work with museums to build social capital. In their interviews, both Stephen and James Smith discussed the ways the Pioneers' work influenced developments, and analysis of the staff interview data demonstrates how the Pioneers had benefited the organisation.

From the Pioneers' perspective, they gained a great sense of pride in making a difference on behalf of others and in seeing the visible impact of their advocacy. In Laila's interview she discussed the 'tick box' nature of some projects she had been involved in. This resonates with Lynch (2011b), who discusses how museums can invite communities in to 'rubber stamp' their ideas. Lynch draws on Cornwall's (2008b) term 'empowerment-lite' to describe the way that communities can feel disillusioned when a museum falls short of genuine collaboration. Laila's comments indicated that this project had gone beyond the 'tick box' approach to create a more equitable and in-depth form of participation, and could be considered to have moved beyond 'empowerment-lite' into the realm of self-empowerment.

Drawing on Adam's (2003) levels of empowerment, it can be seen that empowerment occurred during this project on the individual, interpersonal and group levels. On a personal level, the Pioneers' learnt different forms of empowering knowledge, as well as skills that were transferable beyond the project and which could support a group level of advocacy. As the nature of power is relational, the processes of group advocacy involved them exerting an influence on the Centre at the interpersonal level through the development of social capital.

However, when critiquing the emancipatory principles, Oliver (1997) raises a concern that it is difficult to locate the point at which empowerment takes place, as the effects of research might manifest themselves long after the project is over. For the Pioneers, it is difficult to predict the long-term outcomes of the research. However, tangible ways that the Pioneers have been empowered can be identified in the data. These include an increased awareness of issues relating to disability prejudice, increased knowledge and skills of how to go about changing exclusionary practices, an increase in self-esteem and an increase in the confidence to enact change. Shakespeare (1996b) states that he has major reservations with the concept of emancipatory research and its ability to achieve major change. For young people at a transitional point in their lives, however, these changes are significant and will help them to challenge inaccessible or exclusionary practices at college, in workplaces, with service providers and even in family settings. Margaret summed up this issue in her interview:

I feel that we empowered the young people [...] [to] challenge some of their perceptions about themselves, perceptions about the world, beliefs about what they can and cannot do. [...] What comes out the other end is

a young person who feels valued. [...] they've got that self-esteem and that self-confidence about themselves, so they're empowered to take control of their lives.

Returning to Adam's (2003) levels of empowerment, in terms of community empowerment it is clear that the wider disability community will benefit from the Pioneers' work. However, it is unclear whether this constitutes community empowerment. Research with the wider disability community would need to be undertaken to assess this issue.

Dalrymple and Burke (2006, 107) state that this process of empowerment 'serves to counteract the oppressions that shape and inform the lives of those who do not have access, or have limited access, to the power structures of society'. It is interesting that in accordance with Arnstein's (1969) model, the Pioneers gained access to decision-making on the partnership rather than citizen control level, as the Centre did not hand over power of the decision-making process during the refurbishment. However, this does not seem to have prevented the Pioneers from being empowered by the research, and it did not prevent them from influencing decision-making. Indeed, their input into the interpretive approach was on a sophisticated level. Their sense of empowerment seems to have come from being able to challenge the Centre on its practices and witnessing the Centre acting on their advice.

As shown in figures 47 and 48, the process of the Centre becoming more equitable can be seen as a continuum and in future projects the Centre and the Pioneers could experiment further with the issues of sharing power. In future work the Centre might risk the approach of handing over delegated decision-making to the group (one level beneath citizen control on Arnstein's (1969)

ladder). Following Simon (2010), the Centre and Pioneers worked in a collaborative way on this project. Plans for the sculpture follow a hosted approach, which could be a further development in the relationship. Rather than seeing these relationships in dichotomous terms—of power-sharing or a lack of power-sharing—I would argue that a better way forward is for museums to have a planned, progressive approach. Over an extended period of time they could aim to experiment with different approaches relevant to different types of projects. Joint working with communities might focus on taking greater risks to share power. In this way, museums and marginalised communities can work together in a long-term relationship to challenge different facets of institutional power, and also have a reciprocal focus on alleviating issues which contribute to the community's disempowerment and oppression. In this reciprocal approach, progress, equity and empowerment take centre stage in a methodology that mainstreams equalities issues.

## **Conclusion**

This chapter has explored the impact of undertaking emancipatory disability research and the outcomes for the Pioneers, the youth workers, the Centre staff and the organisation. Through an analysis of the outcomes of the process, it has investigated the extent to which the emancipatory principles enabled the Pioneers to benefit from the research, and whether they were supported to empower themselves. The different levels of empowerment that were achieved at the personal, interpersonal and group and levels have been examined to assess whether there were wider benefits to the research. It was seen that the Centre made steps towards becoming a more inclusive and equitable

organisation as part of this process, although further changes were needed to fully embed equalities issues across the staff and organisation. The way that staff were influenced by the work of the Pioneers, through training and as a result of my influence as Access Officer, have also been discussed. In the concluding chapter these issues will be placed in a broader context to explore how they apply to the wider museums sector and to other marginalised communities who might seek to engage with and influence museums. An examination of the impact on my own professional practice will also be explored.

## **Concluding Chapter**

This concluding chapter sums up the main issues that came out of conducting emancipatory disability research and examines the wider implications for museum practice and work with marginalised communities. It further considers the implications for museum practices that are specific to disability issues and what this study offers to the field of disability studies. I also reflect on the impact the research had on my professional practice. Furthermore, I look at whether the approach taken to the study was able to answer the research questions. In doing so, I will assess whether this single, in-depth case study's findings have elements that are generalisable to the wider museum sector. It can be argued that the study is especially timely given the increasing interest in issues of power-sharing and community participation in decision-making. Yet, in parallel we are seeing large-scale cut-backs in staffing and funding for work that focuses on issues of access and inclusion.

### **The Implications of Emancipatory Research for Museum**

#### **Practice**

Despite key authors concerns about whether emancipatory disability research is an 'impossible dream' (Oliver 1997), and whether it can have a significant impact on anyone beyond the immediate participants (Shakespeare 1996b), it is clear that it is not only possible to follow the emancipatory principles, but that it is of tangible benefit to all parties involved to do so. I was unable to follow some of the principles due to the research not being commissioned by a disability organisation, which is rare for PhD research, and because I had not involved

disabled people in the choice of case study/research methodologies. Also, the Pioneers did not want to be involved in the data collection, analysis and dissemination process. However, if they had chosen to become involved in this aspect of the research I would have facilitated their involvement.

It became clear at the end of the study that the Pioneers were supported to gain the knowledge and skills needed to empower themselves through the research, and acted as their own agents of change. It can be seen that their empowerment stemmed from a greater 'conscientization' (Freire 1972) of historical prejudices about disabled people, and this connected it to issues in their lives. This was particularly important for a group of young disabled people who were not yet fully aware of the political nature of their exclusion and oppression. Through what Freire calls 'praxis' and 'dialogue' they gained a greater understanding of the barriers that prevented them from engaging with culture; and they learnt the skills to challenge exclusionary or oppressive practices through the development of advocacy skills. Their increased capacity to discuss their needs and the barriers that prevented (and prevent) them from engaging with institutions is a transferable skill, and will benefit them in many areas of their lives. It can be argued that this is where the greatest benefits from the project lie in the long-term changes that are felt long after the project is over.

The increased confidence that the Pioneers gained from seeing the Centre act on their concerns, and the sense that they had made a difference on behalf of other disabled people, were also of importance. The positive affirmation that came from young people gaining a sense of pride in their achievements in contrast to society's view, which predominantly focuses on what they cannot do

or achieve, was significant. The impact of the Pioneers gaining a voice and a sense of their own agency cannot be underestimated.

Therefore, when returning to the primary research question that frames this study: 'How can disabled people be empowered to influence decision-making in museums?'; it is clear that the emancipatory principles are an underlying philosophy that can guide how museums work not only with disabled people, but also with other marginalised communities can support them to gain a voice. Importantly, the principles aid both the planning and implementation of work that seeks to address inequalities. It is also clear when looking at the secondary research questions that there is significance both in the process of undertaking emancipatory practices and the outcomes these practices can achieve. In agreement with Solomon (1976), the learning and changes that are involved in the process are as important as the outcomes.

This study has addressed a significant gap in the literature in relation to the role of emancipatory practices in museums. Silverman (2010) presents ideas about how museums can work in an empowering way at the individual, group and society levels. However, this study goes further, discussing a specific methodology that can be used to implement emancipatory practices, and deconstructing the issues and challenges that are involved in working with museum staff who might not initially be committed to or skilled in equalities work. The study highlights the need to engage in this type of work over a long period of time, which means that results cannot be achieved through short-term projects that have tight deadlines. The research also underscores the need to support groups to build a strong team, and to facilitate the participants' understanding of the museum context and the options on offer. It can be argued

that museum staff seem to have a 'blind-spot' when engaging with people who are unfamiliar with museums. They often forget the long training process that they have undertaken to achieve the position of expertise that they hold.

The study also highlights the need for the museum to support participants to take control of the agenda. There is value in investing the time needed to support groups to reach the point of informed decision-making, and to facilitate their greater understanding of museum practices in order for them to act as 'expert' advocates, activists and supporters. Investing in this process is important, as it means that the expertise that marginalised groups build up can elevate their status so that it is on a par with the expertise of museum staff. This challenges the authority of the museum, which some institutions may not necessarily be comfortable with. Within this study, the Pioneers became valued partners whose embodied expertise about disability and its relationship to the museum context was listened to. Therefore, this research speaks to the wider museum sector, as although it is an in-depth, single case study, these elements are generalisable. Reciprocity, empowerment, gain, political engagement, reflectivity, reflexivity and accountability are universal issues that museums need to consider when engaging with marginalised communities, as are the tensions and challenges that can arise when museums seek to support communities to gain access to decision-making.

Conversely, there are drawbacks and limitations to this approach: it is time-consuming; it involves a significant investment of staff time; there is a need to ensure funding is available to implement changes; staff need to acquire skills to support development work with groups; there are no pre-set outcomes, as the

agenda sits with the community; and it can involve 'unsettling' the status quo.

The next sections pay attention to each of these points in turn.

Clearly, museums will not be able to work to this depth on every project they engage in. Indeed, museums can see different approaches as 'part of their toolbox' when thinking about how to work with communities (Simon 2010). This in-depth approach is particularly challenging in the current economic climate, considering the cuts that learning and access teams are facing. Will museums be able to allocate the staffing and budgetary resources to enable this type of work to occur? One might argue that with reduced resources they will need to concentrate on core services to ensure the continued existence and success of learning and community provision. Whilst this may be a current reality, however, the economic climate is unlikely to remain in the current position, and even in a time of austerity, as Lynch (2011b) reports, there are museums which are committed to focusing their services on the genuine needs of their communities. These museums are considering how to work with communities to enable their greater participation, and so go beyond what Lynch calls 'empowerment-lite' (after Cornwall 2008b). Such museums are exploring ways to involve marginalised communities in decision-making and power-sharing.

This research adds to the debate about power-sharing as currently this discourse does not place an emphasis on what the community gains from its involvement in a museum. According to emancipatory principles, however, a mutually beneficial and reciprocal relationship develops. In this study, the Centre benefited from the Pioneers' expertise and advice, which supported access improvements, and in return, the Pioneers gained a whole raft of new knowledge and skills. In alignment with Kitchin (2000), this approach avoided the potential

pitfall of the Pioneers' knowledge being 'mined' with no direct benefit to them. Although in this study this relationship was to a large extent mediated by myself as Access Officer and researcher, the 'twin-track' approach developed during the action research process, supported the Pioneers to develop their own aims for working with the Centre, whilst parallel work was undertaken to support the Centre staff to ensure that they were ready to listen to the group. Within the process of organisational change there is a need to persuade a critical mass of staff to commit to change if benefits are to be felt across the organisation (Moran and Brightman 2000). Over time the Pioneers and the Centre came into contact once the Pioneers had developed the confidence and advocacy skills needed to lobby for change, and once the Centre was ready to listen to their opinions. This 'twin track' approach adds to the debate on how museums and marginalised communities can enter into the 'contact zone' (Clifford 1997) and share 'radical trust' (Lynch and Alberti 2010), as it describes how they can enter into a dialogue from an initial position where the groups are not in alignment.

The next wider sectoral debate that this study speaks to is the issue of the peripheral nature of work with communities (Black 2006). As discussed in Chapter 6, museum practice in relation to equalities work can be seen to be on a continuum with, at one end of the scale, museums who are not committed or experienced in this area of work, and at the other end of the scale, museums that are not only committed but have worked to create inclusive and equitable organisations. In this study there was a fundamental split between the core values of the Centre and its working practices, a split that was excluding people with a range of impairments. A process of organisational change was led by senior management (Access sponsors) with the support of a specialist Access

Officer (Access champion) and other committed members of staff (Access implementers). This enabled the Centre to move towards becoming a more equitable organisation. In this study it was unrealistic to achieve the end goal through a single project, however longitudinal and in-depth in nature. Similarly, museums that wish to mainstream equalities issues need to commit to sustained, long-term work in this area, with successive projects aiming to move practice forward. As demonstrated by this study, there is a need for staff to be motivated and committed to equalities work, and for them to be open both to their practice being questioned and to the benefits of training. As discussed in Chapter 6, significant difficulties can lie with staff categorised as 'Access followers', 'Access deniers' and 'Access sleepers'.

The importance of staff motivation, commitment, openness and knowledge/skills in relation to equality issues came to the fore when either the Pioneers or I were not allowed an input into plans. Inaccessible decisions were made by the 'Access implementers', 'Access followers' and 'Access deniers', which meant that the site was peppered with inaccessible features at the end of the refurbishment, even when the intention had been to improve access. This highlights the need to more fully embed equalities issues, and for staff to deepen their involvement with disabled people.

In this study, the Pioneers had the opportunity to influence senior management. This is in contrast to many museums, where the responsibility for equalities sits with staff at a relatively junior level. These staff do not always have access to decision-making power in their own work, and therefore find it difficult to facilitate access for external communities. However, in this study discussions between senior management and the Pioneers began a process of the Centre becoming

accountable to an external group. Indeed, on the evening when the Pioneers walked Stephen Smith around the exhibition that he had worked so hard to create and explained all the barriers his team had built into the space, there were indeed 'unwelcome truths' for Stephen to hear (Kemmis 2006). Also, the opportunities for Centre staff to work alongside the Pioneers enabled them to witness the group's difficulties with the site. The staff were no longer unaccountable to a notional group of disabled people; instead they were accountable to a specific group of young people who, at times, stood before them, holding them to account.

This work involved an element of risk-taking for both parties. For the Pioneers, it involved trust that the Centre would be willing to hear them and would act on their advice. If that had not occurred, the research might have negatively impacted on their self-esteem and confidence. For the Centre, it involved handing over the agenda to an external group with no assurances about pre-set outcomes. Fortunately, the Centre had a risk-taking culture and, therefore, was comfortable with this approach. For more 'conservative' museums this might not be as acceptable. In this piece of action research, the Centre entered into a collaborative, participatory relationship with the Pioneers. In future work it might aspire to take further risks and move towards what Arnstein (1969) would call delegated power-sharing or even citizen control, where the authority of the museum is challenged to a greater extent. Indeed, it could be argued that in projects which involve balancing the needs and interests of multiple stakeholders, delegating specific responsibilities for decision-making to specific communities could be of benefit. For example, in the Centre's redevelopment the Pioneers might be placed in a delegated power-sharing relationship

concerning access issues. In a similar way, many museums could move into the role of facilitator, facilitating dialogue between and within communities to create a shared framework for decision-making.

This issue of balancing the multiple needs of different communities in relation to power-sharing is an underdeveloped area of the literature. Power-sharing is most often discussed in relation to work with a single community (Lagerkvist 2006; Lynch 2007; Lynch and Alberti 2010). However, as with *The Journey* exhibition, museums frequently need to consider the needs of multiple audiences. Further research into the realities of power-sharing is needed to take this debate further.

More equitable relationships with communities will challenge museum practice, and could potentially unsettle the status quo, creating difficulties for museums that are not used to sharing their authority. However, as discussed by Clifford (1997), there are inevitable tensions that will arise when museums enter the 'contact zone'. These tensions were evidenced in this study. Museums need to be prepared for tensions to arise, however, they need to be ready to hear 'unwelcome truths' (Kemmis 2006). When entering into a dialogue with marginalised communities about the difficulties and barriers that museums as institutions and environments present to them, being open to difficult conversations will enable partners to move forward together to address the identified issues.

Finally, when thinking about the time-consuming and resource-heavy nature of following an emancipatory approach, it is worth considering the levels of outcomes that can be achieved. In the community outreach mode of working,

the community may enjoy the activities that they are involved in, but there is not necessarily significant benefit to their involvement in short-term or one-off activities. Although the museum may learn more by engaging with new communities, this work rarely has an impact on core priorities or working practices.

The approach that is outlined in this thesis had four levels of outcomes. The Pioneers gained new knowledge and skills, along with a greater sense of their agency and a greater confidence in their abilities. As a group they became skilled lobbyists, and gained the social capital necessary to influence the Centre. As an organisation, the Centre received valuable advice on its redevelopment plans to create a greater range of accessible features on-site. The work with the Pioneers supported the Centre to begin to address the underrepresentation of disabled people's histories, and confronted the issues of institutional disablism that had been built into its very fabric. Through the site and service improvements, the wider disability community saw its history represented, and was better able to experience the Centre's programmes alongside other visitors. Therefore, there are significant and far-ranging benefits to making this kind of investment. Overall, this study goes beyond the confines of a single case study, and addresses specific and significant gaps in the literature in relation to the ways in which museums can engage with marginalised communities.

### **The Implications for Museum Practice: Disability Issues**

Although it is important to consider how the study is generalisable, there are some issues that arise that are specific to museums' work with disabled people. The majority of the literature in this area focuses on museums' responsibilities to

meet disability legislation (Hollins 2004; Smith, Ginley, and Goodwin 2012) and how to tackle barriers to access (Bone, McGinnis, and Weisen 1993; Groff and Gardner 1990; Nolan 1997; Landman et al. 2005). As I previously stated, whilst it is important for museums to receive this guidance, this guidance has not in itself been successful in ensuring that museums are holistically accessible. This can be seen in Weisen's (2008; 2010) dismay at the ways that museums continue to overlook basic issues of access, even in multi-million pound projects where resources are clearly available to address them. There have been important advances in the field, particularly in relation to the representation of disabled people in the museum space and disabled people's roles as activists (Dodd et al. 2008; Sandell, Dodd, and Garland-Thomson 2010). However, there are significant gaps in the literature in relation to the depth of engagement that disabled people can enter into with museums, and the issues relating to how museums can move from focusing on the symptoms of inaccessible practices, to examining the root causes. This gap in the literature points to museum practices which predominantly pay attention to practical matters of 'how to' in relation to disability issues, rather than the underlying beliefs, philosophies and working practices within the museum that cause exclusion and contribute to disabled people's cultural marginalisation. One can refer back to Macdonald's (2006) comparison between old museology that was more concerned with practical matters and the new museology, which explores the conceptual foundations and assumptions behind museums' aims to engage with people. In this context, museums are yet to focus in on the issues behind the scenes which cause exclusionary practices and contribute to institutional disablism. Currently, it can be argued that museums do not pay enough attention to the depth of engagement that they could achieve with disabled people. This thesis goes

some way to addressing this gap in the literature, as it presents an approach that enables disabled people to engage in an in-depth way with museums. It also helps museums to consider how they might mainstream disability issues through a process of organisational change. In this study, this depth of engagement supported the Pioneers to give realistic and nuanced advice, which in turn helped the Centre create an inclusive approach to museum interpretation.

### **Impact on My Professional Practice**

The process of undertaking emancipatory research with the Pioneers, and the issues explored in relation to empowerment, reciprocity, power-sharing and mainstreaming of equalities issues advanced my knowledge and skills as a practitioner in ways that could not have been achieved purely through professional practice. It enabled me to stand back and examine my approach to senior management, and consider how to support colleagues negotiate organisational changes. I have therefore seen a great benefit in the way that theory and research can influence professional practices. From my professional experience, many organisations do not understand that by focusing on short-term outreach-style projects, they engage with communities only on the museum's terms, and that this approach rarely supports an examination of the exclusionary practices that are preventing the community's inclusion. By working in an in-depth way I have advanced my knowledge and skills as a change agent and as an advocate for marginalised communities. Moving into senior management enabled me to see how I could act in a leadership role as an Access sponsor to drive the agenda forward.

## **Implications for Research Practices and for Disability Studies**

One of the interesting outcomes of implementing emancipatory action research is learning what the additional perspectives offered by disability studies can add to this research methodology. Authors such as Zuber-Skerritt (1996), Kemmis (2001) and Ledwith (2011) discuss how people can be empowered by their involvement in action research, as there is an emphasis on action to address inequality. However, this body of literature does not specifically address the outcomes for the people involved. As with discussions on power-sharing in museums, there is little discussion of the multiple ways in which participants can benefit. Since this body of literature does not place an emphasis on reciprocity, this sub-field would benefit from a greater understanding of emancipatory principles.

When looking at the disability literature, emancipatory research is seen to be a central development for the field, yet there is little written on the detailed realities of undertaking the research process, nor on the key issues involved in supporting disabled people to gain control of the research agenda. This study has therefore added to the field's understanding.

This research also adds to a growing body of literature on ableism and normalcy, spearheaded by authors such as (Kumari Campbell 2001; 2008; 2009) and Davis (2010). These authors turn the spotlight on able-bodied people to look at the way society treats disabled people. This study has looked at the staff's working practices and whether they were committed to change. It has parallels with Tregaskis's (2003) research which emphasises the 'interface' between non-disabled staff at leisure centres and disabled people. However, in

terms of focusing on staffing and the issue of disability mainstreaming, there is no literature available which looks at the cultural sector. Indeed, the cultural sector at large is an underrepresented area of the disabilities studies literature. In particular, the role that museums play in the public representation of disability history and disabled people's access to culture is largely overlooked. Therefore, this thesis adds to the field of disability studies through its focus on the cultural sector.

## **In Summary**

Overall, what can be seen is that museums have much to learn from emancipatory disability research practices. Although the central case study focuses on a Holocaust museum, this piece of research could have been undertaken in any type of museum as it fundamentally looks at disabled people's right to access culture, rather than specifically examines museums that aim to have socially responsible roles within society. Although the emancipatory principles were developed from within the field of disability studies, they sit alongside a wider tradition of emancipatory research and anti-oppressive practices that aim to address social inequalities. The principles that underpin this study - reciprocity, empowerment, gain, political engagement, reflectivity, reflexivity and accountability - could shape the development of both future research and museums' work with a wide range of marginalised communities. Simon's (2010) discussions centre on the role of the 'Participatory Museum'; I think there is a role for the 'Emancipatory Museum', one that seeks to develop a reciprocal and empowering relationship with marginalised communities based on the communities' agendas, and with an aim to challenge power inequalities at

the core of the museum. This study has also demonstrated that museums have the potential to act as sites of liberatory education and support the self-empowerment of marginalised communities. For the Pioneers, the development of advocacy, team building, life and employment skills will open up new opportunities, enabling them to overturn what Solomon (1976) describes as power-blocks created by the internalisation of oppression and the way that oppressive practices have limited their life opportunities. At the end of the project they were left in a better position than when they started.

Concluding this thesis, I come full circle, back to the letter of complaint and a group of young people who dedicated nearly two years of work to a project in which they were highly invested, and end on what the Pioneers got out of the process. As Margaret indicated in her interview:

They didn't know if they'd make a difference when they arrived. Well you only had to look at that stair lift to know they [the Centre] didn't understand... I think the life skills that they've learnt, the history, [that] they've learnt about themselves... they will take with them for the rest of their lives because they've had that experience now [...] And I think they feel that they can make a difference [...] there's nothing greater than the feeling of achievement, is there?

# **Appendix 1: List of Interview and Pioneers' Session**

## **Data**

### **Interviews with Pioneers**

John Georgehan: 26th November 2008

Katie Hutchinson: 26th November 2008

Laila Dannourah: 5th October 2008

Lorraine Quincey: 5th October 2008

Michael Pell: 26th November 2008

Keiron Stobbs: 26th November 2008

### **Interviews with Youth Workers**

Margaret Clement: 8th October 2008

Audrey Garner: 3rd and 7th October 2008

Pam Ellison: 2nd October 2008

### **Interviews with The Holocaust Centre Senior Management**

Stephen Smith: 27th October 2008

James Smith: 10th October 2008

Marina Smith: 19th October 2008

### **Interviews with The Holocaust Centre Staff**

Due to issues of informed consent, staff members below Chief Executive level have been anonymised. Additionally, the staff did not give consent for their job titles to be included in the study. Therefore, the details that can be given in relation to the interviews are: 20 members of staff (plus retired founder Marina Smith) were interviewed in October 2008. These members of staff worked in the following areas: primary education, secondary education, training with professional groups, administration, finance/HR, fundraising, visitor services, design, marketing/PR, project management and maintenance work.

## **List of Pioneers' Sessions**

Session 1: 27<sup>th</sup> January 2007

Session 2: 5<sup>th</sup> March 2007

Session 3: 24<sup>th</sup> March 2007

Session 4: 14<sup>th</sup> April 2007

Session 5: 14<sup>th</sup> May 2007

Session 6: 2<sup>nd</sup> July 2007

Session 7: 16<sup>th</sup> July 2007

Session 8: 30<sup>th</sup> July 2007

Session 9: 10<sup>th</sup> September 2007

Session 10: 24<sup>th</sup> September 2007

Session 11: 8<sup>th</sup> October 2007

Session 12: 12<sup>th</sup> November 2007

Session 13: 3<sup>rd</sup> December 2007

Visit to The Imperial War Museum: 13<sup>th</sup> January 2008

Session 14: 18<sup>th</sup> February 2008

Session 15: 10<sup>th</sup> March 2008

Session 16: 14<sup>th</sup> April 2008

Session 17: 21<sup>st</sup> April 2008

Event to remember the disabled people who were killed in the Holocaust: 11<sup>th</sup> May 2008

Session 18: 12<sup>th</sup> May 2008

Session 19: 16<sup>th</sup> June 2008

Session 20: 14<sup>th</sup> July 2008

Session 21: 21<sup>st</sup> July 2008

*The Journey* exhibition launch event: 7<sup>th</sup> September 2008

Session 22: 21<sup>st</sup> September 2008

Session 23: 20<sup>th</sup> October 2008

## **Appendix 2: The Holocaust Centre Staff Interview**

### **Questions**

#### **General Information**

1. Date
2. Name of person being interviewed
3. Job title
4. How long have you worked for the Centre?
5. What does your job involve?
6. How would you describe The Holocaust Centre?
7. What role do you think it plays in society?
8. What does it stand for?
9. What impact do you think it has on visitors?
10. Do you think that disabled people have a similar experience on-site, or are they affected by any barriers to accessing the experience?
11. If they are, how are they affected?
12. How would you define the term disability? What do you think it means?

#### **Disability Access at the Centre**

1. Can you describe any changes to access that you have observed at the Centre over the last 2 years (or since you have worked for the organisation)?
2. Are you aware of the work that has been carried out by the Pioneers group at the Centre?
3. How accessible was the Centre before we started working with the Pioneers group?
4. How do you think the Centre has benefited from working with them?
5. What impact do you think the young disabled people have had on the Centre?

6. Have you seen any changes to staff attitudes about disability access?
7. Have you seen any changes to the way that the staff approach their work?

### **Your Work**

1. Do you think about disabled people's needs in your work?
2. Have you always worked like this, or is it something that has happened in response to advice given through consultation with disabled people?
3. Has it changed your approach to your job?
4. How highly do you prioritise the need to be inclusive?
5. Has this changed over the past 2 years?

### **Disability Training**

1. Did you attend the disability training in May?
2. What did you learn from attending the training?
3. What was the most memorable element of the training?
4. What was the most important thing that you learnt?
5. Was there anything that you heard or discussed which surprised you?
6. How would you rate your knowledge of disability issues before the training?
7. How would you rate your knowledge of disability issues after the training?
8. What issues would you like further training on?

### **11th May Event**

1. Did you support the disability event on 11th May? If yes, what was your role?
2. How well did the training help prepare you for the disability event?
3. Were there any issues which arose in supporting people which surprised you on the day?
4. How well do you think we coped as a staff team with supporting a large number of disabled people with lots of different needs?

5. Were there any issues that it raised for you?
6. What did you realise about disabled people's experiences of visiting our Centre?
7. Did it change the perception of the service we offer for disabled visitors?
8. What are your reflections on the disability event in terms of the content of the programme?
9. What was the most memorable part of the day for you?
10. What did you think about dedicating the plaque and rose in the gardens?
11. Why do you think disabled people appreciate our efforts to represent the disability history of the Holocaust?
12. Where you aware of the disability history of the Holocaust before the event?
13. Where you aware that there were any links between the ways that disabled people were treated during the Holocaust to modern issues around prejudice?
14. What do you think we should do as an organisation in response to disabled people's interest in this history?

### **The Holocaust Centre Now**

1. What do you think about disability access at the Centre now?
2. What are the elements that the Centre is now doing well?
3. Could you describe how access has been incorporated into the recent improvements across the site: gardens, café, main exhibition?
4. Could you describe how access has been incorporated into the new Journey exhibition?
5. What disability issues do we still need to work on?
6. Are these any issues that you think the Centre has not prioritised?
7. Do you think there are any factors which are supporting changes to access?
8. Do you think there are any issues which are preventing changes to access?
9. How do you think the Pioneers group has influenced changes?
10. Do you think staff at all levels are supportive of access improvements?

## **Annex 1: What Happened After the Research Ended**

As discussed in Chapter 4, the first session with the Pioneers commenced on 27th January 2007 and the last session was recorded on 20th October 2008, although I continued to work with the group until December 2008 when I left my post at the Centre. In Chapter 6 I discussed the extent to which the Pioneers were able to achieve the aims that they had created for their work with the Centre. At the end of the data collection period they had reached the point with the sculpture project that they had put in a grant application to the Arts Council to fund the design and installation of this artwork. They had given a significant input into the design of The Journey exhibition and the partial refurbishment of the main Holocaust exhibition. At the close of the fieldwork the organisation was not fully accessible either in terms of its working practices or physical, sensory and intellectual access to the Centre and its programmes. However, it had made significant steps forward towards this goal.

What happened though after the audio recorder stopped and the work of the Centre continued? This annex aims to provide an anecdotal postscript to the thesis to discuss some of the changes that occurred at the Centre, and to demonstrate some of the longer term impacts of the research. It will explore what happened at The Holocaust Centre and with the Pioneers.

### **Post-fieldwork Changes at The Holocaust Centre**

After I left my post in December 2008, the Centre faced significant challenges. The effects of the 2008 UK recession started to be felt at the Centre. It receives no direct funding from national or local government and is reliant on the income

that it raises through its admission charge, programme fees, cafe, shop and publishing revenue streams. Historically, it had attracted funding from private donors, grant and trust and charitable foundation sources, along with source of sponsorship. Pre-recession, some of the largest sources of funding came from individual donors and from trust/foundation sources from the Jewish community. Many of the private donors were wealthy business people, and the trust/foundation funds were linked to interest on investments. With the recession, regular donors and the availability of funding sources/sponsorship significantly reduced. The eventual outcome of this in 2009 was a full staffing restructure with the staff being reduced to eight members from an original team of 20. The Centre re-orientated its focus around its core programmes aimed at primary and secondary schools, and much of the additional work that it undertook with adult groups, the Police and probationary services along with development work was cut. Therefore, the Centre did not have the funding available to continue the post of Senior Access and Collections Manager once the Heritage Lottery Fund grant programme had been completed.

Without additional fieldwork, with this scale of cuts and reorganisation, it is difficult to speculate what long term impact the action research with the Pioneers had on the Centre. However, at the end of the research the Centre had significantly improved its accessibility, which will support long term access for disabled people to the site. With the remaining staff, the knowledge that they gained in terms of disability issues, and its implications for their work, will also hopefully have a long term impact.

## **Post-fieldwork: The Pioneers**

Post launch of The Journey exhibition the Pioneers' work focused on the sculpture project. Unfortunately, the grant bid to the Arts Council was not successful, and an alternative source of funding on the scale that was needed to develop, install and interpret a sculpture was not forthcoming. However, Margaret Clement was able to find an alternative funding source through Nottinghamshire County Council which supported the development of the Pioneers' ideas in an alternative art form. The Pioneers worked with a film maker to create a piece of drama that they acted in, which represented the disability history of the Holocaust and the experiences of disabled people. This powerful piece of drama was turned into a DVD and educational resource entitled 'Ignored Voices' which was distributed to youth groups, schools and colleges in Nottinghamshire. One of the resources on the DVD was a 'talking heads' section where the Pioneers' talked about their experiences of creating the drama and the impact that it had on them as young disabled people.

This alternative project therefore enabled them in the long term to realise their vision in a different format, and thus build on the knowledge and skills that they developed during the sculpture project. As a longer term outcome of this project the DST is currently working on setting up an arts performance company for young disabled people, which will aim to empower young disabled people, and will be based on the methodology developed during this thesis.

In terms of the individual Pioneers' long term development, as the majority of them moved on from the service Margaret did not have information about many of the Pioneers to pass on post-research. The one Pioneer that she had kept in

long term contact with was Kerry Wheatcroft. As previously discussed at the outset of the project due to Kerry's variation of Asperger's syndrome, she found social interaction with others difficult to bear. At the start of the project she was unable to sit in the room with the group for any length of time, and when she was able to cope with being in the room she sat with her back to the table and her arms folded. Over time she became more comfortable being part of the group and was able to communicate her needs without speaking. She also took on the role of secretary for the group, and typed up minutes of the sessions, emailing meeting dates and correspondence to the Pioneers and youth workers. This allowed Kerry to find a niche in the group and a sense of purpose which she enjoyed. It also allowed her to communicate in a way that she felt comfortable. This role became pivotal to the group in terms of its organisation, and Kerry gained confidence through it. Towards the end of the project she started to help with administration tasks in the DST office and they enabled her to think about possible future career options post-college. Margaret informed me that currently Kerry has an administrative job for a social enterprise which supports young disabled people to run a smoothly bar. She therefore has a job in a team environment, and Margaret directly attributes this long term development to the Holocaust project. It is clear that the project allowed Kerry to grow and develop personal and employment skills that have had a direct impact on her life path. Whilst the specifics of the contribution of the Holocaust project cannot be identified without further research, it is interesting to hear anecdotally how the project changed Kerry's life. It would also be interesting to conduct research to identify the extent of the project's impact on the other Pioneers.

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